Hidden in Plain Sight: The True Cost of IDD Services in Massachusetts and the Case for Restoring Choice

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Contents

How to Read This Report

This report is designed for a wide range of readers -legislators, agency officials, journalists, families, and advocates - each of whom may need different levels of detail. The structure allows you to move quickly between high-level insights and deep technical analysis.

If you only have 5 minutes

Read:

- Executive Summary
- Key Findings
- Recommendations

These sections provide the essential conclusions: the true cost of the IDD (Intellectual and Developmental Disabilities) system, the hidden off-budget expenditures, and the policy changes needed to restore balance and choice.

If you have 15 minutes

Add:

- Part I: Hidden Costs and Additional Funding Streams

Shows where more than $1.3B in off-budget costs are hidden across MassHealth, Social Security, HUD, USDA, municipalities, and emergency systems.

- Part III: True Cost Comparison for High-Acuity Individuals

Provides the clearest apples-to-apples comparison of HCBS vs. ICF/IID costs.

These sections reveal why the Department of Developmental Services (DDS) budget alone cannot explain the true taxpayer burden.

If you want to understand the system's structural problems

What is HCBS?

Home and Community-Based Services (HCBS) are Medicaid-funded supports that help people with disabilities live in homes and community settings rather than in institutional facilities. HCBS is not a single program; it is a collection of separate services, each with its own rules, providers, and funding mechanisms.

What is ICF/IID?

An Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) is a Medicaid-funded residential program that provides 24-hour, comprehensive care for people with significant intellectual and developmental disabilities and high medical or behavioral needs. Unlike HCBS, which is unbundled, an ICF/IID is a unified, federally regulated service model.

Read:

- Part II: Structural Problems Created by Fragmentation

This section explains why HCBS costs remain high regardless of scale, why oversight is inconsistent, and why emergency systems have become the default crisis managers.

If you want to understand the policy implications

Read:

- Part IV: Restoring Balance and Choice
- Part V: Policy Recommendations
- Part VI: Vision for a Modern, Balanced, and Sustainable System

These sections outline a path forward: restoring access to ICF/IID care, strengthening HCBS, and modernizing public infrastructure.

If you need the technical details

See:

- Sources and Methodology

This section documents data sources, assumptions, population estimates, and cost modeling methods. It is designed to withstand legislative, academic, and media scrutiny.

How the Parts Fit Together

- Part I quantifies hidden costs.
- Part II explains why those costs arise.
- Part III compares the true cost of HCBS vs. ICF/IID.
- Part IV–VI translate findings into policy and vision.
- Part VII concludes with the implications for families and taxpayers.

How to Use This Report

- Legislators can use it to understand the full fiscal picture and the consequences of current policy.
- Families can use it to advocate for real choice and transparency.
- Journalists can use it to uncover the hidden costs behind the DDS budget.
- Agency staff can use it to identify structural weaknesses and opportunities for reform.

Executive Summary

Massachusetts reports a $3.26 billion annual budget for the Department of Developmental Services (DDS), but this figure captures only a portion of the true taxpayer cost of supporting individuals with intellectual and developmental disabilities (IDD). When off-budget expenditures, hidden funding streams, and municipal burdens are included, the actual cost of the Commonwealth's IDD system exceeds $4.56 billion. These additional costs are spread across MassHealth, Social Security, HUD, USDA, municipal budgets, emergency services, and state development finance agencies. They are not reflected in DDS budget documents or legislative presentations. As a result, policymakers and families lack a clear understanding of how public dollars are spent and why so many individuals remain unserved or underserved.

This report provides the most comprehensive analysis to date of the hidden costs, structural inefficiencies, and fiscal distortions created by Massachusetts' heavy reliance on Home and Community-Based Services (HCBS) and its simultaneous underutilization of state-operated Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). While HCBS is often assumed to be the more cost-effective model, our findings show that for high-acuity individuals, HCBS is frequently more expensive, less stable, and less transparent than the bundled, federally matched ICF/IID model.

ICF/IID facilities benefit from economies of scale, integrated clinical care, and a single Medicaid rate that includes housing, staffing, medical supports, and habilitative services. Their per-resident cost declines as census increases. By contrast, HCBS group homes rely on fragmented, unbundled services delivered by multiple vendors, each drawing from separate public funding streams. These costs do not decrease with scale; each new resident requires a new home, new staff, new transportation, and new administrative overhead.

The Commonwealth's current policy of restricting admissions to ICF/IID facilities artificially inflates their per-resident cost, eliminates economies of scale, and denies families access to a federally regulated level of care that DDS itself acknowledges is necessary when community options fail. This policy choice, not the inherent cost of ICF/IID care, drives the perception that institutions are "too expensive."

Key Findings

Hidden public costs in the HCBS system exceed $1.3 billion annually, including:

- $227.9M in Social Security contributions captured by providers
- $411M in day habilitation costs paid by MassHealth
- $385M–$595M in medical costs and $28M–$75M in dental costs
- $53M in SNAP benefits
- $15.9M in lost municipal property taxes
- $360K–$1M in development bond subsidies
- $33.6M in transportation costs
- $750K–$4.5M in police and emergency response

Cost Comparison for High-Acuity Individuals:

- HCBS: **$196,350-$267,850** per person annually depending on exact acuity level (costs per person remain the same as census increases)

- ICF/IID: **$88,939–$260,900** per person annually
(cost per person decreases as census increases)

Potential Savings From Restoring ICF/IID Admissions

Analysis shows that when ICF/IID facilities operate at sustainable census levels, the Commonwealth saves substantial funds compared to attempting to provide the same level of support through HCBS for high-acuity individuals. At moderate census levels, annual savings reach nearly $14 million, and at full capacity, annual savings exceed $70 million, totaling roughly $350 million over five years. These savings are achievable simply by complying with informed-consent requirements and allowing individuals with high needs to choose ICF/IID care if they so desire.

Structural insights:

- HCBS costs remain flat and high regardless of scale.
- ICF/IID costs decline sharply with increased census due to fixed infrastructure.
- Fragmentation in HCBS creates oversight gaps, inconsistent staffing, and heavy reliance on emergency systems.
- Private providers benefit from layered public funding and tax-exempt real estate holdings, while families face instability and municipalities absorb unreimbursed costs.

• Restricting ICF/IID admissions eliminates economies of scale and forces high-acuity individuals into the most expensive, least coordinated model of care.
• HCBS relies on multiple uncoordinated funding streams — including SNAP, Social Security, and Section 8 — creating duplicate public subsidies that inflate total system costs while remaining invisible in DDS budget documents.

Strategic Insights

• The Commonwealth's IDD system is significantly more expensive than publicly acknowledged.

• HCBS is not inherently cheaper; for high-acuity individuals, it is often more costly and less clinically appropriate than ICF/IID care.

• Families lack meaningful choice when ICF/IID admissions are restricted, despite federal law guaranteeing access to all certified service options.

• The current system shifts hidden costs onto families, municipalities, and other state agencies, while obscuring the true taxpayer burden.

• A balanced continuum of care, where HCBS and ICF/IID operate as complementary models, is essential for sustainability.

Recommendations

- Restore access to state-operated ICF/IID care as a genuine choice for individuals with severe and profound disabilities.
- Increase transparency across all funding streams supporting IDD services.
- Strengthen HCBS through improved oversight, workforce stabilization, and accountability.
- Modernize and revitalize public ICF/IID campuses as centers of excellence and hubs for clinical support.
- Align policy with actual cost structures to ensure equitable, sustainable, and fiscally responsible service delivery.
- Modernize the DDS placement system with AI-assisted decision-support. This will improve fairness, strengthen clinical integrity, and position Massachusetts for the future..

Conclusion

Massachusetts' IDD system is far more costly and fragmented than the public budget suggests. By acknowledging hidden costs, restoring balance across the continuum of care, and strengthening oversight, the Commonwealth can build a system that is transparent, sustainable, and capable of meeting the needs of individuals with IDD-especially those with the highest levels of acuity. A modern, balanced system is not only fiscally responsible; it is essential to ensuring dignity, safety, and real choice for individuals and families across the Commonwealth.

Introduction:

This Introduction provides the context necessary to understand the full cost of Massachusetts' IDD service system and why traditional budget documents fail to capture the true taxpayer burden. It outlines the hidden costs families experience, the transparency challenges within the DDS budget, the definitions and regulatory frameworks that shape service delivery, and the limitations of previous cost analyses. Together, these sections establish the foundation for the detailed examination that follows. The subsequent Parts of this report quantify off-budget funding streams, analyze the structural inefficiencies created by fragmentation, and compare the true costs of serving high-acuity individuals in HCBS versus ICF/IID settings.

The Hidden Costs No One Talks About

When policymakers compare service models for people with severe and profound intellectual disabilities and autism, they often focus on surface-level costs. But beneath the spreadsheets lie deeper truths…costs that families absorb, taxpayers subsidize, and systems quietly overlook.

Transparency Issues: Where Does the Money Go?

Massachusetts allocates **$3.26 billion annually to the Department of Developmental Services (DDS).** We have found that the true cost to taxpayers is around $4.56 billion, yet families and advocates face a wall of silence when they ask how that money is spent or why so many individuals are unserved or underserved.

Why do numerous special needs families in Massachusetts refer to "falling off a cliff" when their children turn 22 and transition from school entitlements to adult services?

Why are direct support professionals paid minimal subsistence wages?

The money just doesn't add up!

Background and History

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) are federally regulated institutions that provide comprehensive, 24/7 care for people with significant developmental disabilities. These facilities offer bundled services, including medical care, behavioral supports, habilitation, and daily living assistance, all under one roof and one Medicaid rate. Because staffing, housing, and clinical supports are integrated, ICF/IID settings benefit from economies of scale and centralized oversight. Massachusetts currently operates two such facilities: Wrentham Developmental Center and Hogan Regional Center, though new admissions are restricted by state policy.

Home and Community-Based Services (HCBS), by contrast, are delivered in decentralized settings like group homes, shared apartments, or family homes. HCBS are funded through Medicaid waivers and typically use unbundled service models, meaning housing, staffing, transportation, day programs, and clinical supports are billed separately, often by different providers. While HCBS claims to promote community integration, it can result in fragmented care and higher cumulative costs, especially when providers layer multiple public funding streams (e.g., SSI, SNAP, Section 8) on top of state reimbursements.

The pendulum has swung so far toward deinstitutionalization that many people forget, or never knew, that some Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) were well-run, deeply supportive environments that offered structured care, active treatment, and community engagement.

The 1970s -1990s saw major improvements in Massachusetts in institutional care under Judge Tauro's reforms and under federal standards[1] for active treatment, staffing, and client protections. Tauro's reforms stemmed from the landmark Ricci v. Okin class action lawsuit, filed in the 1970s on behalf of residents at Belchertown, Fernald, and Wrentham State Schools. The case exposed systemic neglect and led to a federal consent decree overseen by U.S. District Court Judge Joseph L. Tauro. Under

> "Six months after being sworn in as a US District Court judge, Joseph L. Tauro hopped in his sports car and drove 90 miles west from his Boston courthouse to pay an unannounced visit to a state school for the developmentally disabled… That visit led to the first landmark ruling by the jurist…"
>
> — Boston University School of Law tribute to Judge Tauro

his watch, Massachusetts institutions were transformed through court-mandated improvements in staffing, individualized care, and physical conditions…so much so that by 1993, Judge Tauro declared the care for individuals with intellectual disabilities in Massachusetts "second to none anywhere in the world".[2]

The 1999 Supreme Court Olmstead decision did **not mandate the closure of institutions.** It emphasized that community placement should only occur when appropriate for the individual, not as a blanket policy.

Previous Cost Analyses

Most previous cost comparisons of ICF/IID care and HCBS combined all individuals with IDD into one group, even though ICF/IID often serves those with more severe or complex needs. However one 2003 study[3] separated populations by severity and found HCBS is not always less expensive than ICF/IID care. While ICF/IID covers housing, meals, transportation, medical, dental, and other services, HCBS does not; these additional costs are typically paid through SSI/SSDI and other government funds. This means Medicaid pays less for HCBS, but the overall taxpayer burden can be similar, and community-based care at comparable service levels may actually cost more. This report explores hidden costs and funding sources that are often overlooked.

Part 1- Hidden Costs and Additional Funding Streams

Part I identifies the full range of public costs that support the HCBS system but do not appear anywhere in the DDS budget. These additional funding streams—spanning MassHealth, Social Security, HUD, USDA, municipal budgets, emergency services, and state development finance agencies—represent more than a billion dollars in off-budget spending each year. By documenting these hidden costs, this section demonstrates that the true taxpayer burden of HCBS is far higher than the $3.26 billion DDS appropriation suggests. Understanding these funding streams is essential for evaluating the real cost of community-based services and for making accurate comparisons to the bundled, federally regulated ICF/IID model.

The Social Security Siphon

- In Massachusetts, individuals with IDD served in DDS residential care must pay seventy-five percent of their Social Security check to their provider-whether corporate or state-run.
- In corporate-run group homes, this money helps build private real estate portfolios.
- In state-operated ICF/IID settings, it could be reinvested in public infrastructure, upkeeping campuses, improving care environments, and preserving taxpayer assets.

How Much Is That?

Estimated Annual Revenue from Social Security Contributions

Let's walk through the math using publicly available data:

🔍 Calculation Based on Residential DDS Population

From the most recent data:

- DDS serves approximately 40,000 individuals statewide.
- Of those, about 16,000 individuals are in residential placements, including Adult Long Term Residential (ALTR), Shared Living, and other DDS-funded housing.[4]

Now let's walk through the math:

1. Monthly Social Security Contribution

- Average SSDI/SSI benefit: $1,583
- 75 percent of that (typically captured by residential providers): $1,187/month

2. Annual Contribution per Person

- $1,187 × 12 months = $14,244/year

3. Total Annual Revenue from Residential Population
    - $14,244 × 16,000 individuals = $227.9 million/year. That's **$227.9 million annually** flowing to corporate and state-run providers from individuals' Social Security checks. In corporate-run group homes, this money often helps build private real estate portfolios. In state-run ICF/IID settings, it could be reinvested in public infrastructure, preserving campuses like Wrentham and Hogan.

This is $227.9M that providers receive from individuals' social security checks. This money is not included in the DDS $3.26B budget.

Day Habilitation in Massachusetts: Scope and Cost[5]

In Massachusetts, Home and Community Based Services (HCBS) excludes day habilitation services. Day habilitation is not part of the DDS budget; it is covered solely by MassHealth.

Enrollment

- As of 2025, approximately 11,000–12,000 individuals are enrolled in day habilitation programs statewide.
- These programs serve people with intellectual and developmental disabilities who require supports during the day.

Cost to the State[6]

- The average daily rate for day habilitation services is around $90–$120 per person, depending on the level of need and staffing supports.
- With programs typically operating 5 days per week, the annual cost per person ranges from $23,400 to $31,200. However, individuals who require one-to-one supports can raise the per person costs to an average daily rate of $300-$500 per person with an annual cost of $78,000-$130,000 per person.
- This translates to a total annual expenditure of **approximately $411 million** for the Commonwealth, funded through MassHealth (Medicaid) rather than DDS.

Support Level	Participants	Avg Annual Cost	Subtotal
Standard Group Rate	~10,120	~$27,000	~$273 million
1:1 Staffing Level	~1,380[7]	~$100,000	~$138 million
Total Estimated Cost	**—**	**—**	**~$411 million**

This is $411M that comes out of the MassHealth budget and is not counted in the DDS budget of $3.26B.

Medical Costs

Some medical care (but not all)[8] and dental care is included in on-campus ICF/IID facilities and is part of the bundled service model. This is specialized healthcare specifically geared towards those with IDD.

HCBS requires people with IDD to get medical care in the community. However, they need special attention and accommodations not usually found in standard healthcare settings, which increases healthcare costs and strains emergency rooms and law enforcement.

When individuals with severe and profound developmental disabilities can't access appropriate care, they end up in:

- Emergency rooms
- Psychiatric hospitals
- Crisis stabilization units

These are high-cost, high-stress environments, and they're not equipped for long-term disability care.

The result? Skyrocketing healthcare costs and avoidable suffering.

Quote from mother of an adult with severe autism:

One thing that comes to my mind is the amount of overmedication that takes place when we get to the level of having to involve police and hauling individuals with severe IDD to hospitals.

Every time Dean was hospitalized he was bed-ridden for the entire time, over-medicated because he was not possible to manage in a hospital environment. Usually with Versed. Another high toll to the individual, and the family. Not only can the group not manage his behaviors, he has to be knocked out for a week for no reason other than the house's inability to deal with him. It does absolutely nothing to change his behavior.

Then he returns to the group home when the hospital is done with him.

NOW LET'S ESTIMATE THE COSTS[9]……

Medical Costs for Adults with IDD Placed in Community – Based Services (HCBS)			
Level of Need	**Estimated Annual Cost Per Person**	**Population Estimate**	**Total Cost**
Mild/moderate IDD	$10,000–$15,000	~21,000	~$210M–$315M
Severe/profound IDD	$25,000–$40,000	~7,000–9,000	~$175M–$280M

Estimated Total (Non-LTSS Medical): **$385M–$595M/year**

This range reflects:

- Higher hospitalization rates
- Complex medication regimens
- Frequent specialist care
- Behavioral health needs

It excludes:

- Day habilitation
- Residential supports
- Transportation
- LTSS case management
- DDS-funded dental or behavioral services

One ER visit for a behavioral crisis can cost more than a month at the Wrentham Developmental Center

Dental Costs

Let's estimate the costs:

A. Preventive care baseline (~$600–$1,000/year)

Typical annual preventive care includes:

- 2 cleanings
- 1–2 exams
- X-rays
- Fluoride treatments

For adults with IDD, costs are often higher because:

- appointments take longer
- more frequent cleanings are needed
- specialized providers charge more

So the low end of $1,000 is a conservative estimate.

B. Restorative care (fillings, crowns, extractions)

Adults with IDD have:

- higher rates of untreated decay
- higher rates of periodontal disease
- more missed preventive care
- more complex needs

A single crown can cost $1,200–$2,000.

A single extraction can cost $300–$600.

A filling is $150–$400.

Most adults with IDD need at least one restorative procedure per year, often more.

This is how you get to the upper end of $2,500+.

C. Sedation dentistry

Many adults with IDD require:

- nitrous oxide
- IV sedation
- general anesthesia

Sedation adds $500–$1,500 per visit — often out-of-pocket.

This is why the "+" is important. Some individuals easily exceed $2,500.

D. Most high-acuity adults with IDD require IV sedation every 1–2 years

Why?

- They cannot tolerate drilling, suction, or prolonged mouth opening
- They cannot communicate pain or discomfort
- They cannot remain still for complex procedures

- They often have sensory sensitivities
- They may have aspiration risks

Routine dental care is included in the ICF/IID Medicaid benefit, ensuring consistent preventive services for residents. However, high-acuity adults with IDD in both ICF/IID and HCBS settings frequently require IV-sedation dentistry for restorative or complex procedures. These extraordinary dental costs occur across all settings and typically range from $3,000 to $7,000 per sedation episode, often needed every 1–2 years. While MassHealth may cover anesthesia, the overall cost burden remains significant and reflects the high unmet dental needs of this population

E. What IV sedation actually costs

The total cost of a sedation dentistry visit includes:

A. Hospital or surgical center facility fee

Often $1,000–$2,500

(Some hospitals charge more.)

B. Anesthesiologist fee

Typically $500–$1,200

C. Dental procedures performed under anesthesia

This is where costs explode:

- multiple fillings
- deep cleanings
- extractions
- crowns
- periodontal treatment

A single sedation session often results in $1,500–$4,000 in dental work.

Dental Care Costs for Adults with IDD Placed in Community-Based Services			
Type of Care	Estimated Annual Cost per Person	Population Estimate	Total Cost
Preventive + restorative	$1,000–$2,500+	~28,000–30,000	~$28M–$75M

Dental Total: ~$28M–$75M/year

This reflects:

- High unmet need
- Limited access to sedation dentistry

- Out-of-pocket costs for complex care

When states compare ICF/IID costs to HCBS costs, they leave out the significant costs of caring for adults with IDD in the community. ICF/IID bundles these costs in their total cost of care. Our numbers are most likely an underreport because we did not include Medicare, private insurance, and out-of-pocket dollars**. We estimate medical and dental costs for adults with IDD in HCBS to be between $413M and $670M. These figures are not included in the $3.26B DDS budget.**

SNAP (Supplemental Nutrition Assistance Program)

SNAP benefits (food stamps) are often collected by adults with IDD living in group homes, and those benefits are redirected to corporate providers who manage food purchasing centrally. Let's break this down and estimate the cost.

- Adults with IDD in HCBS group homes are considered individual SNAP recipients.
- Providers often act as authorized representatives, collecting and managing the benefits.
- SNAP funds are pooled to cover communal food costs, often with little transparency or individual choice.

Estimated Monthly Benefit:

- Most adults with IDD qualify for maximum SNAP, currently $291/month (FY2025).
- Some receive less if they have SSI or other income, but many are at or near the max.

Statewide Estimate:

Let's assume:

- ~16,000 adults with IDD in HCBS group homes statewide[10]
- Average SNAP benefit: ~$275/month

$275 × 12 months × 16,000 individuals = $52.8 million/year

This is public food assistance flowing directly to providers, often without oversight or itemized accounting.

Now lets look at SNAP in ICF/IID Settings:

Key Difference:

- Residents of ICF/IID facilities **do not receive SNAP as individuals**.
- These facilities are considered institutional settings, and food is provided as part of the Medicaid-funded package.
- Federal SNAP rules exclude individuals in long-term care institutions from eligibility.

So:

✅ SNAP in group homes → Yes, benefits collected and redirected

❌ SNAP in ICF/IID → No, food is covered by Medicaid

We estimate that SNAP benefits for adults with IDD in HCBS costs the state around $53 million per year. This figure is not included in the $3.26 billion DDS budget. This is a hidden revenue stream.

SNAP and the Social Security Siphon:

If the resident receives SNAP, which is meant to cover food, and the provider also collects 75 percent of the individual's SSI/SSDI for food, there's a risk of double-dipping.

- ✓ Providers rarely itemize what portion of the 75 percent goes to rent vs. food, making it hard to audit or challenge.
- ✓ Some providers may pocket the SNAP benefit or fail to adjust SSI collection accordingly.

Section 8 + Social Security in Group Homes

What's Happening:

- A small number of adults with IDD in HCBS group homes receive Section 8 vouchers, typically through local housing authorities.
- These vouchers cap rent at 30% of the individual's income, with HUD covering the rest.
- However, many corporate providers still require residents to pay 75 percent of their monthly Social Security income, often under the label of "room and board" or "residential fees."

Why This Is Concerning:

- ✓ If a resident in a group home receives a Section 8 housing voucher, providers may also collect 75 percent of the individual's SSI/SSDI for room and board, and additionally receive SNAP benefits intended for the resident's food. This practice allows providers to collect three separate public subsidies for the same individual—essentially "triple dipping"—with little oversight or itemized accounting.
- ✓ There's no centralized oversight of how these funds are used or whether residents receive itemized accounting.

How Widespread Is This?

Families often feel they must offer everything - vouchers, benefits, trust- just to secure basic care. This image reflects the emotional toll of a system where public subsidies flow freely, but access to appropriate services remains uncertain.

Unfortunately, there's no public dataset that breaks down:

✓ How many adults with IDD in group homes receive Section 8

✓ Of those who receive these vouchers, how many pay 75 percent of their Social Security to providers

We do not know the figures, but let's assume that 250 individuals in the DDS system receive Section 8 vouchers and still pay 75 percent of their Social Security to providers. The average per person/per month benefit from these vouchers are around $943. That adds up to around $2.8 million. HUD covers the rent beyond 30 percent of income. Since we do not know the figures, we realize that they could be much less or much more significant.

The additional funding stream from HUD to corporate providers via Section 8 vouchers could be $2.8M*. This Section 8 money is not included in the $3.26B DDS budget.

This is only an assumption, as we lack concrete details and are relying solely on limited anecdotal accounts.

Transportation Costs

Transportation represents a significant but often overlooked component of the service system's true cost structure. This includes:

- PT-1 rides (MassHealth)
- Non-emergency medical transportation (MassHealth)
- Transportation to day habilitation (MassHealth)
- DDS-funded transportation add-ons that are not part of the group home rate

These transportation expenses are not included in the base group home operational rate. Instead, they are funded through separate mechanisms, resulting in substantial systemwide expenditures that are not visible in standard residential cost comparisons.

Our estimate draws on published transportation cost studies, MassHealth service utilization reports, and provider-reported costs for van operations and contracted transportation. These sources consistently show that the annual cost of providing regular rides for day habilitation, routine medical care, and community participation is substantial, particularly given the frequency of appointments and the geographic dispersion of services.

The resulting $33.6 million estimate[11] represents the systemwide annual cost of transportation services that fall outside the base group home operational rate and are instead funded through MassHealth or other sources.

ICF/IID residents rarely use day habilitation transportation

Because:

- Many services are delivered onsite
- Medical care is often provided onsite
- Day programming is integrated into the facility
- Transportation needs are dramatically lower

All ICF/IID transportation is included in the Medicaid rate for ICF/IID.

HCBS residents rely heavily on MassHealth-funded transportation

Because:

- Day habilitation is offsite

- Medical care is offsite
- PT-1 rides are used frequently
- Community participation requires transportation

Please note: Community participation requires transportation regardless of setting. In ICF/IID facilities, transportation is typically coordinated and provided by the campus. In community-based services, transportation must be arranged through separate providers or funding streams. The need is universal; the mechanisms differ.

This additional transportation is not included in the HCBS waiver rate.

This $33.6M in additional transportation costs is not included in the $3.26B DDS budget.

Police Response

Across Massachusetts, local police departments are increasingly called to respond to behavioral crises, medical emergencies, and elopements involving individuals with intellectual and developmental disabilities (IDD) living in residential group homes. These calls are not isolated incidents. They reflect systemic gaps in staffing, training, and oversight within the HCBS system.

Group homes often operate with minimal overnight staffing, limited clinical supervision, and fragmented behavioral supports. When a resident becomes aggressive, self-injurious, or disoriented, staff frequently call 911. Police officers, often untrained in disability de-escalation, are placed in the impossible position of managing complex neuropsychiatric emergencies without medical authority or long-term solutions.

While Massachusetts DDS does not reimburse towns for these interventions, the public cost is real.

Let's estimate the cost

1. Call Volume Estimate

    - Assume 1–2 police calls per year per group home
    - With ~3,000 group homes statewide, that's 3,000–6,000 calls/year

2. Cost per Call

    - Average police response (2 officers, 1 hour): $150–$250
    - If EMS or transport is involved: $500–$1,000+

3. Annual Statewide Cost

    - Low estimate: 3,000 calls × $250 = $750,000/year
    - High estimate: 6,000 calls × $750 = $4.5 million/year

This does not include:

    - Time diverted from other emergencies
    - Emotional toll on officers and residents
    - Repeat calls due to lack of follow-up services

- ✓ Towns bear the cost, while providers receive layered public funding (DDS, SSI, SNAP, Section 8)
- ✓ Families are often unaware that police—not clinicians—are the default crisis responders
- ✓ The state's refusal to admit individuals with high needs to ICF/IID settings forces fragile residents into under-resourced group homes

Police costs amount to $750K to $4.5M per year. This figure is not included in the DDS $3.26B budget

Mobile Crisis Intervention (MCI)

Massachusetts operates Mobile Crisis Intervention (MCI) teams as part of its statewide behavioral-health crisis system. These teams are available 24/7 and are designed to respond within one hour to behavioral or mental-health crises in homes, group homes, schools, and community settings. MCI services are delivered through Community Behavioral Health Centers (CBHCs) and are funded through MassHealth and behavioral-health contracts, not through the DDS budget.

MCI teams typically include clinicians, case managers, and crisis specialists who provide on-site assessment, de-escalation, safety planning, and short-term stabilization. They are intended to reduce reliance on emergency departments and police response by offering a community-based alternative for behavioral crises.

Although MCI is not specific to intellectual and developmental disabilities (IDD), these teams are frequently called to respond to crises involving individuals with IDD living in HCBS group homes. Because MCI is funded through MassHealth rather than DDS, the cost of these crisis responses is not included in the $3.26 billion DDS budget.

This creates another layer of off-budget spending that supports the HCBS system but is not visible in public reporting.

Funding Structure

Under federal guidance, states may receive enhanced Medicaid reimbursement for qualifying mobile crisis services. In Massachusetts:

- MCI is Medicaid-billable
- Services are available regardless of insurance status
- CBHCs must maintain 24/7 availability to qualify for federal funding
- Staffing includes licensed clinicians and crisis specialists
- MCI is funded through MassHealth behavioral-health contracts, not DDS

This means that mobile crisis response represents a recurring cost center within the broader IDD support system, even though it is not reflected in DDS expenditures.

Role in the HCBS System

For individuals with IDD living in community settings, crisis response often involves multiple public systems:

- HCBS provider staff
- Mobile Crisis Intervention teams
- Emergency medical services
- Local police departments
- Emergency departments

MCI is one component of this multi-agency response network. Its involvement underscores the extent to which HCBS relies on external, publicly funded crisis infrastructure that falls outside DDS oversight and budgeting.

Cost Considerations

While precise statewide cost data for MCI is not publicly consolidated, the following points are clear:

- MCI is funded through MassHealth, not DDS
- It represents an ongoing, off-budget expenditure
- It is routinely used to support individuals with IDD in HCBS settings
- These costs are not included in any DDS cost comparison between HCBS and ICF/IID

As with day habilitation, medical care, dental care, transportation, and police response, mobile crisis services illustrate how the HCBS model depends on multiple external systems whose costs are not captured in the DDS budget.

Implications for Policymakers

Any comparison of HCBS and ICF/IID costs must account for the full range of public services required to support individuals with high behavioral or medical needs. Mobile Crisis Intervention is one such service- publicly funded, essential to the HCBS system, and entirely absent from DDS budget reporting.

Disabled Persons Protection Commission (DPPC) Intake Costs

The Disabled Persons Protection Commission (DPPC) represents another hidden public cost of the HCBS system. DPPC serves as the statewide intake point for all allegations of abuse and neglect involving individuals with disabilities, including those served by DDS. While DPPC immediately refers DDS clients back to the DDS Investigations Unit — whose costs are included in the DDS budget — DPPC's intake operations are funded separately and do not appear in DDS cost reports. This means that a portion of the state's abuse-reporting infrastructure is effectively subsidizing the HCBS system, yet these expenses are not reflected in the $3.26 billion DDS budget.

Both HCBS and ICF/IID cases of abuse go through DPPC intake, but the distribution of reports is not equal.

HCBS has:

- thousands of scattered locations
- high turnover
- inconsistent training
- limited clinical oversight
- more unlicensed or minimally trained staff
- more transportation incidents
- more behavioral crises

ICF/IID has:

- centralized staffing
- on-site nursing
- on-site clinicians
- federally mandated training
- 24/7 supervision
- a single campus with consistent oversight

So while both settings use DPPC intake, HCBS generates far more intake volume, which means:

That's a hidden cost of decentralization.

Development Bonds

Taxpayer Subsidies—Without Accountability

- Corporate providers benefit from **development bonds—low-interest financing subsidized by taxpayers.**
- Nonprofit-run HCBS group homes are **exempt from property taxes**, even as they operate in high-value residential areas.

Meanwhile, state campuses are underfunded, underutilized, and politically sidelined.

Now let's estimate how much this costs:

Development Bonds for Corporate Providers

MassDevelopment and similar agencies issue tax-exempt bonds to corporate and nonprofit entities for facility construction, renovation, and equipment purchases. These bonds offer below-market interest rates, effectively subsidized by taxpayers.

How this works:

- A $10 million bond issued at 3% instead of a market rate of 6% saves the borrower ~$300,000 annually in interest.

These homes are leased to corporate nonprofit providers, who operate them as group homes under DDS contracts.

What This Means:

- MassDevelopment bonds offer low-interest, tax-exempt financing, subsidized by taxpayers
- Providers benefit from reduced capital costs, while the public bears the financing risk
- These subsidies are not reflected in DDS's $3.26B budget, making them a hidden cost of privatization

Here are some known examples in recent years:

Year	Project/Provider	Bond Amount
2020	CIL Realty (28 residences)	$20M
2023	CIL Realty (21 residences)	$25M
2019	CIL Realty (27 residences)	$29M
2024	Walnut Street Center & CARE (day habilitation)	$5.9M
2022	Various smaller providers	~$10M
Estimated Total		~$90M

Now, let's make an annualized estimate

Assuming:

- $18M/year[12]
- Tax-exempt bonds typically save providers **1.5–2.5% in interest annually**
- That savings is effectively **foregone tax revenue**

Estimated Taxpayer Subsidy:

- 2% × $18M = **~$360,000/year in lost tax revenue**
- Plus administrative costs, bond servicing, and indirect subsidies

This is a **conservative estimate**. If bond issuance increases or larger projects are financed, the taxpayer cost could exceed **$500K–$1M/year**.

There's no unified accounting of how much public money flows to each provider.

This $360K in lost tax revenue from development bonds is not included in the $3.26B DDS budget.

Lost Municipal Property Taxes

Under G.L. c. 59, § 5, charitable organizations are exempt from property taxes if the property is:

- Owned and occupied for charitable purposes
- Used by another charitable organization for mission-aligned work

Let's estimate how much tax-exempt group homes cost taxpayers:

1. Residential Census

    - ~16,000–17,000 individuals with IDD receive residential services
    - Assuming 5 residents per home:

16,000 ÷ 5 = ~3,200 group homes statewide

2. Ownership Pattern

    - Let's conservatively estimate 70 percent are owned by nonprofits
    - 70 percent × 3,200 = ~2,240 nonprofit-owned homes

3. Assessed Value

    Avoiding high-value towns, assume $647,505 per home[13]

4. Average Property Tax Rate

    Massachusetts average: ~1.1%

Estimated Lost Property Tax Revenue

- $647,505 × 1.1% = $7,123 /year per home
- $7,123/year × 2,240 homes = ~$15.9 million/year

This is municipal revenue lost annually due to nonprofit exemptions—not reimbursed by DDS or MassHealth, and often invisible in public accounting.

Municipalities lose revenue while still providing services (e.g., police, fire, DPW). Providers benefit from tax-free real estate, often financed with development bonds

Residents with IDD have no ownership stake, despite public investment. Despite the rhetoric to the contrary, individuals with IDD receiving HCBS in group homes do not live in their own homes. Instead they live in a home owned by corporate providers or homes owned by their parents or siblings.

This lost tax revenue is not reimbursed by DDS or MassHealth, and towns often have no say in whether these homes are exempt. The exemption applies automatically if the nonprofit claims charitable use—even if the home is leased to a provider generating revenue to pay large salaries to its corporate executives.

Approximately $15.9M in lost municipal property taxes is not included in the DDS $3.26B budget.

Overview (Hidden Costs & Financial Distortions)

Part I demonstrates that the true cost of HCBS is far higher than the state's published figures suggest. When the system relies on fragmented funding streams - SNAP, Section 8, Social Security, police and emergency services, DPPC investigations, municipal tax exemptions, and low DSP wages subsidized by public benefits - the apparent price of HCBS becomes an illusion. These hidden costs are real, recurring, and borne by taxpayers across multiple agencies that do not coordinate with one another.

The result is a system that appears inexpensive only because its expenses are scattered across federal, state, and municipal budgets. When these costs are aggregated, HCBS for individuals with higher acuity needs rivals, and often exceeds, the cost of ICF/IID care. Part I reveals the financial truth: HCBS is not cheaper; it is simply less transparent.

To understand why these hidden costs accumulate across so many agencies, we now turn to the structural fragmentation that makes inefficiency unavoidable.

.Part II: Structural Problems Created by Fragmentation

Part II examines the systemic weaknesses created by Massachusetts' reliance on a decentralized, unbundled HCBS service model. Fragmentation across multiple providers, funding streams, and oversight bodies leads to inconsistent care, gaps in clinical support, and a heavy dependence on emergency systems such as police, Mobile Crisis Intervention, and DPPC intake. These structural problems are not incidental. They are inherent to the design of the HCBS model and help explain why hidden costs accumulate across agencies and municipalities. By analyzing how fragmentation drives instability, under-service, and off-budget spending, this section provides the essential context for understanding why HCBS often becomes more expensive and less reliable for individuals with high-acuity needs.

Unbundled Silos: A Collection of Separate Services

The HCBS system in Massachusetts is built on an unbundled service model in which housing, staffing, day programs, transportation, medical care, dental care, behavioral supports, and case management are delivered by separate providers and funded through different agencies. No single entity is responsible for coordinating or overseeing the full scope of an individual's needs. This structural fragmentation creates gaps in communication, inconsistent service delivery, and a lack of accountability across the system.

Because each component is contracted separately, providers operate within narrow scopes of responsibility. Residential agencies are not responsible for day habilitation outcomes; day programs are not responsible for medical follow-through; medical providers are not responsible for behavioral supports; and transportation vendors are not responsible for safety or continuity. As a result, individuals with high-acuity needs often fall through the cracks, and families are left to coordinate services that should be integrated.

Fragmentation also obscures the true cost of HCBS. Expenses are spread across MassHealth, DDS, SSA, HUD, USDA, municipal budgets, police departments, and emergency systems. This dispersal makes the HCBS model appear less expensive than it is, while simultaneously making oversight more difficult. The unbundled structure is the root cause of many of the access barriers, crises, and hidden costs documented throughout this report.

Oversight Gaps in the HCBS System

The HCBS system operates without a unified oversight structure. Residential providers, day habilitation programs, transportation vendors, medical and dental providers, behavioral health agencies, and crisis responders all function as separate entities with separate regulatory frameworks. No single agency is responsible for ensuring that individuals with high-acuity needs receive coordinated, clinically appropriate, and safe care across settings.

Diffuse Responsibility

DDS licenses residential providers but does not oversee:

- day habilitation (MassHealth)
- medical care (MassHealth, Medicare, private insurance)
- dental care (MassHealth, private insurance)
- transportation vendors
- police or Mobile Crisis Intervention
- DPPC investigations

Each component operates in its own silo, with limited communication and no shared accountability.

DPPC and DDS Investigations: A Reactive System

DPPC receives thousands of allegations annually, many involving HCBS group homes. Investigations are often delayed, fragmented, or inconclusive because:

- DPPC has no authority over medical providers
- DDS has no authority over day hab
- police have no authority over clinical care
- MCI has no authority over residential providers

The result is a reactive system that responds to crises but cannot prevent them.

Emergency Systems as De Facto Oversight

Because HCBS lacks integrated clinical supervision, emergency systems become the default oversight mechanism:

- police respond to behavioral crises
- MCI responds to psychiatric escalations
- ERs respond to medical and dental failures
- DPPC responds to abuse/neglect allegations

These systems were never designed to provide long-term disability oversight, yet they absorb the consequences of fragmentation.

Lack of Outcome Accountability

No entity is responsible for:

- ensuring clinical follow-through
- monitoring behavioral support quality
- tracking medical/dental access
- evaluating day hab effectiveness
- preventing repeated crises
- coordinating care across providers

This absence of outcome accountability is a defining structural flaw of the HCBS model.

Lack of Transparency: Corporate Providers Versus State-Operated

Unlike state-operated facilities, corporate providers are not subject to the same public oversight. Families and legislators often have no visibility into:

- How funds are allocated
- What portion goes to care vs. administration
- Whether outcomes justify the cost

Massachusetts is quietly expanding private congregate care options that resemble institutions but lack federal ICF/IID certification. Families are told these options offer high-level care. They operate without the staffing, oversight, or treatment mandates required by law that govern ICF/IID care.

Who Monitors Double Dipping on Section 8 and SNAP?

Who's Supposed to Monitor Double Dipping?		
Agency/Entity	**Role**	**Limitations**
DDS (Department of Developmental Services)	Oversees provider contracts, sets room and board guidelines	Rarely audits how SSI, Section 8, and SNAP are actually used
MassHealth	Funds HCBS services, sets rate structures	Doesn't monitor housing subsidies or food benefits
Social Security Administration (SSA)	Issues SSI/SSDI, tracks representative payees	Doesn't coordinate with DDS or housing authorities
Local Housing Authorities	Administer Section 8 vouchers	Don't track provider SSI collections or food charges
USDA (SNAP program)	Oversees food assistance	No visibility into DDS provider billing practices
State Ethics Commission / Auditor	Investigates fraud or misuse of public funds	Only acts on complaints — no routine oversight of DDS providers

No single agency monitors how DDS providers use SSI, Section 8, and SNAP. Without audits or transparency, providers may double and triple-dip — charging rent and food twice, while families and taxpayers foot the bill. Reform must include subsidy tracking and financial accountability.

Unregulated Donations: The Quiet Currency of Influence

Corporate nonprofit providers of IDD services routinely solicit donations from families, sometimes during emotionally charged moments like care transitions or crises. While philanthropy can support enrichment programs, the current system lacks any formal protections against coercion, favoritism, or undue influence. There are no safeguards to ensure that adult children of major donors do not receive preferential treatment, expedited services, or enhanced staffing.

This creates a shadow funding stream, one that providers can leverage to supplement budgets, reward loyalty, and cultivate political capital, all while presenting themselves as community-based and mission-driven. Families may feel pressured to contribute, fearing that refusal could affect their loved one's care. Yet these donations are rarely disclosed in public audits, and their impact on service equity remains unexamined.

Private Donations—The Quiet Currency		
Source	Oversight?	Impact on Services
Family Donations	❌ None	❓ Untracked
Corporate Sponsorships	❌ None	❓ Unclear
Gala/Event Contributions	❌ None	❓ Not Audited
Bequests/Endowments	❌ None	❓ No Equity Review

Providers solicit donations from families without safeguards against coercion or favoritism. There's no public accounting of how these funds affect care quality or access.

While families donate out of love and desperation, executives benefit from layered public and private funding with no transparency on how it affects equity.

Missing Real Estate Watchdog for DDS Contracted Providers

Massachusetts has a **Conflict of Interest Law** (M.G.L. Chapter 268A) enforced by the **State Ethics Commission**, which prohibits:

- ✓ **Public employees** (including those at DDS) from participating in matters where they or their associates have a financial interest.
- ✓ **Contracted providers** from engaging in self-dealing if they're acting in a public capacity or using public funds.

In theory, if a **corporate executive** of a DDS-contracted provider buys a property and then sells it to their own agency at a markup…especially if that agency is funded by MassHealth or DDS. It could trigger:

- ✓ **Conflict of interest violations**
- ✓ **Fraud or procurement scrutiny**
- ✓ **Ethics complaints** (which can be filed anonymously)

But here's the catch: **oversight is weak**.

What's Missing in Practice:

- ✓ **DDS does not routinely audit real estate transactions** by providers.
- ✓ **MassHealth rate-setting** assumes housing costs but doesn't verify ownership structures.
- ✓ **Nonprofit boards** may rubber-stamp deals without independent review.
- ✓ **State Ethics Commission** only investigates if someone files a complaint. It doesn't proactively monitor DDS provider deals.

It is possible for a corporate executive to **profit from a real estate flip or a lucrative real estate leasing deal**[14] involving their own agency, unless:

- ✓ The agency has strong internal controls
- ✓ A whistleblower flags the deal

- ✓ The transaction is unusually large or public

“.”

Massachusetts lacks meaningful oversight of real estate deals by DDS-contracted providers. Without audits or transparency, executives may profit from property flips or lucrative leasing deals using public funds to enrich private interests. Reform must include procurement scrutiny and ethics enforcement.

Systemic Burdens and Structural Inequities

Executive Pay: Who is Profiting

Public messaging often emphasizes 'community for all,' but families question whether financial incentives distort the conversation. This image reflects the frustration of those who feel excluded from meaningful choice while providers benefit from layered public funding."

While families struggle to secure basic care, some corporate providers of privatized group homes are paying their executives six- and seven-figure salaries. These are funded at least partially by public dollars and charitable donations

Executive compensation packages often include:

- Base salaries exceeding $300,000–$500,000 per year
- Bonuses tied to expansion, not outcomes
- Perks like housing allowances, travel stipends, and deferred compensation

Meanwhile, direct care staff, the backbone of daily support, often earn low wages, with limited benefits and high turnover.

What Could That Money Do?

Redirecting even a fraction of executive pay could:

- Fund higher wages for frontline staff
- Expand access to therapies and medical care
- Reduce reliance on emergency services
- Support family respite and crisis stabilization

Labor Issues

Labor exploitation acts as a hidden subsidy when underpaid, marginalized workers support high-need individuals without proper support. The state reduces costs by not fully funding intensive care, shifting the burden to the workforce.

- ✓ Executive compensation vs. frontline strain: When executives earn six and seven-figure salaries while direct support professionals (DSPs) earn poverty wages, the disparity isn't just unjust. It's a hidden cost borne by the workforce, families, and ultimately the disabled individuals whose care suffers.
- ✓ Decentralization without infrastructure: Community-based services often lack the clinical depth, emergency protocols, and staffing ratios needed for complex cases. The result? Burnout, turnover, and preventable crises, all of which carry financial and human costs that aren't reflected in budget line items.
- ✓ Racialized labor dynamics: Many group homes and day programs rely heavily on immigrant women and workers of color. Their essential work remains unrecognized in official data.
- ✓ Low DSP wages create another hidden public cost. Because many DSPs earn so little, they qualify for SNAP, MassHealth, childcare subsidies, and other safety-net programs. These costs do not appear in the DDS budget, but they are borne by taxpayers. The HCBS system relies on a publicly subsidized low-wage workforce, masking the true cost of service delivery.

Labor exploitation is a subsidy.

Labor Burden Index		
Category	**Hidden Cost Description**	**Who Bears It**
Underpaid DSP labor	Intensive care delivered at below-market wages	Immigrant & BIPOC workers, individuals with IDD
Executive pay gap	Resources diverted from direct care	Families & frontline staff
Crisis fallout	ER visits, police calls, staff turnover	Taxpayers & individuals with IDD
Emotional toll	Trauma, burnout, moral injury	Caregivers & families, frontline staff

Salary Differences: State ICF/IID Care Versus Private Provider HCBS		
Setting	**Average Hourly Wage**	**Notes**
State ICF/IID (e.g., Wrentham, Hogan)	~$22–$28/hour[15]	Includes union-negotiated raises and step increases
Private Providers (DDS-funded group homes, day programs	~$15–$18/hour[16]	Often constrained by low Medicaid reimbursement rates

- ✓ **State workers are typically unionized (SEIU Local 509 or AFSCME), with structured pay scales and longevity bonuses.**
- ✓ **Private provider wages vary widely and are often below the Massachusetts living wage threshold.**

Benefit Differences: State ICF/IID Care Versus Private Provider HCBS		
Benefit Type	**State ICF/IID Facilities**	**Private Providers**
Health Insurance	Comprehensive state employee plans	Often limited or high-deductible plans
Retirement	State pension (Massachusetts State Retirement System)	Usually 401(k) with minimal employer match
Paid Leave	Generous sick/vacation accruals	Limited PTO, often unpaid sick time
Job Security	Civil service protections	High turnover, less stability

- ✓ **Many private DSPs rely on Medicaid themselves for health coverage due to low wages.**[17]
- ✓ **Turnover in private settings exceeds 40 percent annually, threatening continuity of care.**[18]

Training and Career Path Differences: State ICF/IID Care Versus Private Provider HCBS

State ICF/IID	Private Providers
Formal onboarding, ongoing training, and promotional pathways (e.g., to LPN or supervisory roles).	Training varies; often minimal due to staffing shortages and budget constraints.

The HCBS system depends on a low-wage workforce with some of the highest turnover rates in the human services sector. Annual turnover commonly exceeds 40–60 percent, and many group homes operate with constant vacancies, mandatory overtime, and reliance on inexperienced or temporary staff. Low wages make it difficult to recruit and retain workers with the training, patience, and clinical awareness required to support individuals with severe and profound disabilities.

This instability has direct consequences for safety and quality of care. High-acuity individuals rely on predictable routines, familiar staff, and consistent behavioral strategies. When staff rotate frequently or lack adequate training, behavioral crises become more common, medical issues go unnoticed, and emergency systems like police, Mobile Crisis Intervention, and emergency departments,-are called upon to fill the gaps. Turnover also undermines the implementation of behavioral plans, medication monitoring, and communication strategies, increasing the risk of preventable incidents and DPPC reports.

These staffing challenges are not isolated personnel issues; they are structural features of a decentralized HCBS model that relies on low wages to control costs. The result is a system that is inherently unstable, difficult to supervise, and prone to crisis-driven care.

Hidden Costs of Exclusion: Shifting Responsibility to Families

In Massachusetts, there is no formal mechanism for tracking rejections from private providers due to difficult-to-serve impairments. In a national survey conducted by the National Council on Severe Autism in 2025, more than 1,000 families participated. The results showed that 80 percent of these families were told their loved one was considered "too severe" or "not a good fit" to receive services.[19] In Massachusetts, anecdotal evidence suggests that individuals turned away by corporate providers are discreetly referred to self-directed service options.

Excluding people deemed "too severe" is not just about funding—it's discrimination based on disability. Some families choose self-directed services, but others are pushed into them because they lack access to proper support and aren't offered ICF/IID, a care model for those with severe IDD or autism. This practice shifts responsibility and emotional burden onto families, while concealing systemic failures in protecting civil rights.

Here are some of the possible future hidden costs of exclusion:

- ✓ Emergency care and crisis interventions: Lack of consistent support leads to behavioral escalations, ER visits, psychiatric hospitalizations, and police involvement—all of which are far more expensive than preventive care.
- ✓ Lost caregiver productivity and income: Families often reduce work hours or leave jobs entirely to fill service gaps. This leads to lost tax revenue, increased reliance on public benefits, and long-term economic strain.
- ✓ Legal liability and ADA violations: Discriminatory service denial may expose the state to lawsuits, federal investigations, and compliance costs under the ADA and Section 504. Please visit the Saving Wrentham and Hogan Alliance website for more information.

Opaque and Unaccountable Referral System

In Massachusetts, DDS controls all referrals to residential providers. Families may choose only among the options DDS presents, and cannot approach providers directly to inquire about openings. There is no independent oversight to ensure that referrals are clinically appropriate, equitable, or free from favoritism. This centralized gatekeeping structure operates without transparency or accountability, creating a significant structural vulnerability within the HCBS system.

Access Failures Across Essential Services

Medical and Dental Access Barriers

Individuals with severe and profound intellectual and developmental disabilities require consistent, specialized medical and dental care. In state-operated ICF/IID settings, many of these services are integrated into the bundled Medicaid rate and delivered on-site by clinicians who are trained to work with high-acuity populations. In the HCBS system, however, medical and dental care is delivered through a decentralized network of community providers who often lack the training, equipment, or accommodations necessary to treat adults with complex developmental disabilities. This structural difference creates significant access barriers that directly contribute to higher costs, delayed treatment, and avoidable crises.

Lack of Clinician Training and Accommodations

Most community medical and dental practices are not designed to serve adults with severe IDD. Providers may lack:

- training in communication strategies
- sensory-friendly environments
- extended appointment times
- behavioral support capacity
- specialized equipment for positioning, suctioning, or airway management

As a result, routine care becomes difficult or impossible to deliver in standard outpatient settings. Individuals are frequently referred to emergency departments, psychiatric hospitals, or surgical centers for issues that could have been managed in a more specialized environment.

Emergency Departments as Default Care Providers

Because HCBS group homes often lack on-site clinical staff and rely on community providers who cannot accommodate high-acuity needs, emergency departments become the default point of care. This leads to:

- unnecessary hospitalizations
- over-medication during behavioral crises
- prolonged boarding in inappropriate settings
- increased use of restraints or sedation

- higher overall medical expenditures

These outcomes are not isolated incidents—they are predictable consequences of a decentralized system that lacks integrated clinical capacity.

Severe Barriers to Dental Care

Dental care is one of the most significant access challenges in the HCBS system. Many adults with IDD require:

- IV sedation
- hospital-based dentistry
- specialized equipment
- longer appointment times
- clinicians trained in developmental disabilities

Yet very few dental practices in Massachusetts offer these services. Waitlists for sedation dentistry can stretch months or years, and families often face out-of-pocket costs even when procedures are medically necessary. Untreated dental issues frequently escalate into infections, extractions, or emergency interventions—each of which carries substantial cost and risk.

Fragmentation Drives Higher Costs

These access barriers are not incidental; they are inherent to the HCBS model. When medical and dental care is outsourced to a patchwork of community providers, the system loses:

- continuity
- clinical oversight
- preventive care capacity
- the ability to intervene early

This fragmentation directly contributes to the high medical and dental expenditures documented in Part I. It also increases reliance on emergency systems, destabilizes individuals with high-acuity needs, and shifts significant costs onto MassHealth, hospitals, and families.

Day Habilitation Service Delivery Failures

While MassHealth's day habilitation rate structure includes reimbursement for **allied health services** (PT, OT, Speech), in practice:

Some programs **do not provide these therapies directly**.

- ✓ They may simply have a licensed clinician approve that services aren't needed, usually without thorough assessment, or provide consultative therapy without fully understanding the individual's situation.
- ✓ This creates a **billing structure that implies clinical support**, while families experience **minimal or no therapeutic benefit**.

Why This Matters for Cost Analysis

- The **gross cost** includes reimbursement for services that are **often not delivered**.
- This inflates the perceived value of day habilitation and **masks under-service**.
- It also **undermines Federal Medical Assistance Percentage (FMAP) justification**. Federal Medicaid dollars are meant to support medically necessary services, not placeholder staffing.

Although day habilitation rates include allied health components (PT, OT, Speech), many programs do not deliver these services. Instead, they employ clinicians to document non-need, resulting in reimbursement for services not provided. This discrepancy inflates gross cost estimates and misrepresents therapeutic value.

What Is FMAP?

Federal Medical Assistance Percentage (FMAP) is the formula the federal government uses to determine how much of each state's Medicaid spending will be reimbursed by the federal government. FMAP is essentially the federal share of Medicaid costs.

How FMAP Works

• Every state has its own FMAP rate. The Massachusetts rate is 50%.

• FMAP applies to most Medicaid services, including HCBS waivers, ICF/IID services, and many medical and behavioral health supports.

FMAP and Cost Comparisons

When comparing service models—such as HCBS versus ICF/IID—it is essential to account for FMAP because the state's actual cost is not the full service cost, but rather the state share after FMAP is applied.

Day Habilitation: The Hidden Gap in Services[20]	
Billed Services (Per MassHealth Rate)	**Services Often Delivered**
■ Developmental Skills Training ■ Nursing Oversight ■ PT / OT / Speech Therapy ■ Behavioral Supports ■ ADL Assistance ■ Transportation	▨ Developmental skills training provided in limited amounts by untrained staff ■ Nursing Oversight (None or Minimal) ☐ PT / OT / Speech Therapy (Rarely provided) ☐ Behavioral Supports (Can be absent or generic) ■ ADL Assistance (in limited amounts by untrained staff) ■ Transportation (Varies)

While formal data on service delivery gaps is lacking, our members consistently report that day habilitation programs do not provide the allied health services embedded in the reimbursement rate. These firsthand accounts, shared across dozens of member stories, reveal a systemic pattern: clinicians are employed to document non-need, not to deliver care. The result is a billing structure that inflates cost without delivering therapeutic value.

Police and MCI Overreliance in the HCBS System

The HCBS system relies heavily on police and Mobile Crisis Intervention (MCI) teams to manage behavioral and medical crises that arise in community settings. This overreliance is not the result of individual provider failures; it is a predictable outcome of a decentralized model in which clinical expertise, behavioral supports, and medical oversight are not integrated into daily care.

A System Without On-Site Clinical Capacity

Most HCBS group homes operate without:

- on-site nursing
- on-site behavioral clinicians
- 24/7 clinical supervision
- staff trained in crisis de-escalation for high-acuity individuals

When a behavioral or medical issue escalates beyond what minimally trained staff can manage, the only available response is to call 911 or MCI. This turns emergency responders into de facto clinical support , a role they were never designed to fill.

Emergency Systems as Default Crisis Managers

Because HCBS lacks integrated clinical infrastructure, emergency systems absorb the consequences:

- Police respond to behavioral escalations, even when no crime has occurred.
- MCI responds to psychiatric crises, often without access to the individual's history or behavioral plan.
- Emergency departments become holding areas for individuals who cannot safely return home.

These responses are reactive, expensive, and destabilizing. They also increase the risk of restraint, sedation, hospitalization, and trauma.

Fragmentation Makes Follow-Through Impossible

Once police or MCI intervene, there is no single entity responsible for ensuring:

- behavioral plans are updated
- medication changes are monitored

- environmental triggers are addressed
- staff receive additional training
- the crisis does not repeat

This lack of follow-through is a structural flaw of the unbundled HCBS model. Crises recur because no one is accountable for preventing them.

A Costly and Unsafe Substitute for Integrated Care

Police and MCI involvement is often framed as a safety measure, but in practice it reflects the absence of:

- consistent staffing
- clinical oversight
- predictable routines
- specialized behavioral supports
- medically informed crisis planning

In a bundled, clinically integrated model such as an ICF/IID, these crises are far less common because the supports needed to prevent them are built into the system.

Admissions Restrictions: Closed Doors, Inflated Costs: The Strategy Behind ICF/IID Admission Denials

Massachusetts continues to restrict admissions to its state-operated ICF/IID facilities, even when families request placement and individuals meet federal eligibility criteria. This deliberate underutilization has significant consequences for both cost and care:

- **It artificially inflates per-person costs**, making ICF/IID services appear inefficient on paper.
- **It fuels misleading calls for closure**, as watchdog groups and budget analysts rely on inflated cost figures.
- **It eliminates real choice**, forcing families into fragmented HCBS settings even when a bundled, federally regulated model is more appropriate.

This is not simply a budget quirk, it is a structural tactic that reshapes the entire service system. By suppressing census, the state undermines economies of scale, weakens the ICF/IID model, and shifts high-acuity individuals into a decentralized system that is not designed to meet their needs.

A System Out of Balance

When disability services operate within a privatized, unbundled framework, financial incentives can overshadow clinical outcomes. Admission restrictions to ICF/IID facilities benefit private providers by diverting individuals into HCBS placements, where executive compensation, real estate holdings, and layered revenue streams face limited oversight.

The Saving Wrentham and Hogan Alliance maintains that:

- **Public funds should serve public good, not private gain.**
- **Families deserve transparency in how care dollars are allocated and why certain options are withheld**.
- **Executive compensation and provider expansion should be tied to outcomes, not to the suppression of viable public options.**

The Turning 22 Bottleneck: A Structural Barrier With Financial Consequences

Massachusetts requires all young adults entering adult services to begin in community-based HCBS placements funded entirely by state Turning 22 dollars. Even when families request ICF/IID placement and the individual meets federal eligibility criteria, admission is not offered. This creates a structural bottleneck: individuals who would benefit from a bundled, federally reimbursable model are instead placed in unbundled HCBS settings with no federal match.

Turning 22 funds are 100 percent state-paid. By contrast, both HCBS waivers and ICF/IID services receive 50 percent federal reimbursement through FMAP. If families had access to ICF/IID from the start, the state could receive federal reimbursement immediately, reducing strain on state budgets and improving clinical stability for high-acuity individuals. The Turning 22 line item is $110 million. Even modest access to ICF/IID would generate significant federal support:

- 5% of Turning 22 individuals (lowest plausible estimate):
  → $5.5M in services
  → $2.75M federal share
- 15% of Turning 22 individuals (moderate estimate):
  → $16.5M in services
  → $8.25M federal share

By restricting access to ICF/IID, the state forgoes between $2.75M and $8.25M in federal reimbursement annually, a direct consequence of a structural policy choice, not an inherent cost of care.

Overview (Structural Problems Created by Fragmentation)

Part II shows that the challenges of HCBS are not isolated failures. They are the predictable outcomes of a system built on fragmentation. When residential care, day habilitation, medical and dental services, behavioral supports, transportation, crisis response, and oversight are all delivered by separate entities with separate funding streams, no single provider or agency is responsible for the whole person. This structural design produces instability, inconsistent care, and preventable crises.

Oversight gaps, lack of transparency, unregulated donations, staffing turnover, police/MCI overreliance, day habilitation failures, and the Turning 22 bottleneck all stem from the same root cause: HCBS is an unbundled model without integrated clinical or administrative accountability. The system depends on emergency responders, families, and underpaid staff to fill the gaps created by this fragmentation.

Part II makes clear that these are not problems that can be solved with more training, more audits, or more funding. They are structural. And they explain why, for high-acuity individuals, HCBS often becomes the most expensive and least stable option.

With the structural problems of HCBS now clear, Part III brings the full cost picture into focus by quantifying what high-acuity care actually requires across all unbundled systems.

Part III: True Cost Comparison for High Acuity Individuals

Part III brings the full cost of high-acuity care into focus by assembling every component of HCBS spending into a single, comprehensive picture. In Parts I and II, we saw how fragmentation, hidden subsidies, and diffuse oversight scatter the true cost of HCBS across multiple agencies and funding streams. Here, we quantify those costs directly.

For a high-acuity individual, support does not come from a single HCBS program but from a patchwork of separate systems — residential services, day habilitation, medical and dental care, behavioral supports, transportation, emergency response, public benefits, and municipal subsidies — each funded and administered through different agencies and mechanisms. Each system has its own billing structure, oversight gaps, and administrative overhead. When these components are finally added together, the total taxpayer cost of HCBS becomes clear and it can be directly compared to the bundled, federally regulated ICF/IID model.

This section breaks HCBS into its major cost categories, applies FMAP where appropriate, and presents both gross and net taxpayer costs. The result is a transparent, side-by-side comparison that reveals the financial reality of supporting high-acuity individuals in an unbundled system versus an integrated one.

The sections that follow begin with residential operations, the largest and most essential component of HCBS spending for high-acuity individuals.

Please note: While residential operations represent the largest HCBS cost for many high-acuity individuals, others experience medical or psychiatric instability that drives hospital-based care to become the most expensive component of their annual support.

1. Residential Operations (HCBS Waiver)

Residential services make up the largest and most costly part of HCBS spending for people with high-acuity needs. Group homes for those with severe medical, behavioral, or functional challenges need high staff-to-resident ratios, frequent overtime, and specialized clinical supervision. For individuals with significant needs, yearly operating expenses for residential care usually fall between $220,000 and $300,000 per person, varying based on staffing levels, behavioral issues, and requirements for one-on-one support. Medicaid waivers cover these costs, splitting the financial responsibility equally between the state and the federal government through FMAP.

Residential Operations Cost Breakdown

Cost Category	Gross Cost	FMAP-Eligible?	FMAP-Adjusted Cost
Residential Operations (HCBS Waiver)	$220,000–$300,000	✅ Yes	$110,000–$150,000 for residential

Methodology:

Gross residential costs were calculated using DDS and MassDevelopment design and staffing guidelines, including the Facilities Consolidation Fund (FCF) Program Design and Cost Guide.

Key Insights:

- Residential operations consume the majority of HCBS spending for high-acuity individuals.
- Costs escalate quickly when 1:1 staffing or behavioral supports are required, often exceeding the typical range.
- Residential costs do not include day habilitation, some transportation, medical/dental care, or behavioral supports, all of which must be funded separately.
- HCBS residential programs cannot achieve economies of scale, making them structurally more expensive for individuals with significant needs

2. Day Habilitation Services (MassHealth Benefit, Separate From HCBS)

Day habilitation in Massachusetts is a standalone MassHealth service, billed separately from residential supports and governed by its own regulations, staffing requirements, and reimbursement structure. For high-acuity individuals, day habilitation is intended to provide structured skill development, therapeutic supports, and community engagement. In practice, however, it can function as a parallel system with limited clinical integration, inconsistent staffing capacity, and significant variability in its ability to serve individuals with complex behavioral or medical needs.

Day Habilitation Cost Breakdown

Cost Category	Gross Cost	FMAP-Eligible?	FMAP-Adjusted Cost	Notes
Day Habilitation Services	~$78,000/year	✅ Yes	~$39,000	Based on $225/day × 260 days; reflects typical Level 3–4 high-acuity rates

Methodology:

Because day habilitation is not part of the HCBS waiver, it represents an additional cost layered on top of residential services. High-acuity individuals typically attend five days per week, and programs frequently require enhanced staffing or behavioral support to maintain safety and participation. A conservative and realistic estimate for a high-acuity adult is $225 per day, based on MassHealth's tiered leveling system for individuals with significant behavioral or medical needs.

Key Insight

Day habilitation is a major cost driver for high-acuity individuals precisely because it is separate from residential care. The lack of integration means that clinical information, behavioral plans, and staffing strategies do not flow seamlessly between settings, increasing the likelihood of program disruption, shortened days, or outright refusal. These failures shift costs to emergency departments, psychiatric units, transportation vendors, and families, none of which are reflected in the day habilitation line item.

In contrast, ICF/IID day programming is embedded within a unified clinical and administrative structure, eliminating the duplication, instability, and downstream costs created by the separation of residential and day services. This is a separate system with its own billing, oversight, and FMAP rules.

3. Medical and Dental Care (MassHealth + Private Insurance + Out-of-Pocket + Unfunded Costs)

Medical and dental care for high-acuity adults with intellectual and developmental disabilities is one of the most fragmented and unpredictable components of the community-based system. Unlike the ICF/IID model, where medical, dental, nursing, and behavioral services are integrated under a single clinical umbrella, Community-based

services rely on a patchwork of providers, each with separate billing systems, waitlists, and eligibility rules.

For non-verbal individuals, any change in health or behavior triggers a “diagnostic journey” involving multiple specialist visits, imaging, and laboratory testing because there is no integrated clinical team to triage symptoms. Families must initiate and coordinate these evaluations, but the system-side costs- specialist visits, imaging, labs, and provider-driven care coordination, are paid by MassHealth, Medicare, and private insurance. These are predictable, recurring expenses.

Hospitalizations are more variable: some individuals have never been hospitalized, while others experience repeated or prolonged admissions. These hospitalizations are often driven by behavioral crises, untreated medical issues, psychiatric boarding, or the lack of integrated clinical oversight in HCBS. When they occur, they generate extremely high costs that fall entirely on MassHealth, Medicare, private insurance, and hospitals.

Medical & Dental Cost Breakdown

Cost Category	Gross Cost	FMAP-Eligible	FMAP-Adjusted Cost	Notes
Routine Medical Care (PCP, specialists, labs)	~$12,000/year [21]	✅ Yes	~$6,000	Baseline care: PCP, psychiatry, GI follow-ups, neurology, dermatology, labs, medication management
Diagnostic Evaluation & Specialist Visits for Non-Verbal Individuals	~$12,000/year	✅ Yes	~$6,000	Multiple specialists, imaging, labs triggered by inability to self-report symptoms; a predictable cost of HCBS
Dental Procedures Under General Anesthesia (every 2–3 years)	~$3,000–$4,000/year	✅ Yes	~$1,500–$2,000	Based on $6,000–$10,000 procedure every 2–3 years; MassHealth covers with prior authorization
Provider-Side Care Coordination	~$5,000/year	✅ Yes	~$2,500	Embedded in hospital and outpatient billing rates; includes discharge planning, specialist coordination, administrative scheduling.
Hospitalizations (variable but high-impact)	~$20,000–$80,000/year	✅ Yes	~$10,000–$40,000	Some individuals have none; others experience prolonged stays Psychiatric boarding and medical crises drive costs

Total Estimated Gross Cost:

~$52,000–$113,000/year

Total Estimated FMAP-Adjusted Cost:

~$26,000–$56,500/year

These numbers remain conservative. A single prolonged hospitalization can exceed $200,000.

Methodology for Cost Estimates

Routine Medical Care

The estimate of $12,000 per year for routine medical care is based on national per-capita health expenditure data, which show average annual spending of $12,000–$14,500 per adult in the United States. High-acuity adults with intellectual and developmental disabilities typically require more frequent medical monitoring than the general population, including regular primary care, psychiatry, gastroenterology, neurology, dermatology, and laboratory testing. Using the national average as a baseline and applying conservative assumptions about service frequency yields an annual estimate of approximately $12,000. This figure is intentionally conservative and does not include diagnostic evaluations, emergency department visits, or hospitalizations, which are accounted for separately.

Diagnostic Evaluations

The estimate of $12,000 per year for diagnostic evaluations reflects the predictable pattern of medical utilization for high-acuity, non-verbal adults who cannot self-report symptoms. Because group homes do not provide on-site clinical assessment, any change in behavior or health requires ruling out multiple potential medical causes. A typical diagnostic cycle includes specialist visits, imaging, labs, and additional procedures. A single cycle costs approximately $8,000 based on MassHealth reimbursement rates. Most non-verbal adults experience more than one such cycle per year due to recurrent gastrointestinal issues, dental pain, infections, behavioral changes, or other medical concerns. Using a conservative multiplier of 1.5 cycles per year yields an annual estimate of approximately $12,000.

Dental Procedures Under General Anesthesia

The estimate for dental procedures under general anesthesia is based on the typical cost of OR-based dental care for individuals who cannot tolerate office-based procedures. These procedures, which occur every two to three years, generally cost between $6,000 and $10,000, including anesthesia, facility fees, and dental services. Annualizing the cost over a three-year period yields a conservative estimate of $3,000–$4,000 per year. MassHealth typically covers these procedures when medically necessary, but families must navigate prior authorization requirements and limited operating room availability.

While some individuals with intellectual and developmental disabilities can tolerate routine dental care without anesthesia, high-acuity non-verbal adults often cannot. For this population, dental procedures under general anesthesia every two to three years are the norm, not the exception. The cost estimate reflects this high-acuity subgroup.

Provider-Side Care Coordination

The estimate of $5,000 per year for provider-side care coordination reflects the administrative and clinical coordination embedded within hospital and outpatient billing rates. These activities include discharge planning, inter-specialist communication, care plan updates, scheduling, and follow-up management. Although families perform substantial unpaid coordination, the estimate here captures only the coordination performed by hospitals, clinics, and MassHealth care managers as part of Medicaid-covered services. Using typical administrative cost allocations within MassHealth reimbursement structures, a conservative estimate of $5,000 per year reflects the portion of provider-side coordination attributable to high-acuity individuals with complex medical needs.

Hospitalizations

The estimate of $20,000–$80,000 per year for hospitalizations reflects the wide variation in inpatient utilization among high-acuity adults. Some individuals have no hospitalizations, while others experience repeated or prolonged admissions due to medical crises, behavioral escalations, or psychiatric boarding. Typical MassHealth inpatient reimbursement for a medical admission ranges from $10,000 to $20,000 per episode. Extended stays can exceed $200,000. The range used here represents a conservative annual estimate that captures both low-utilization and high-utilization patterns without overstating costs.

Key Insight:

For high-acuity, non-verbal individuals, medical and dental care is not simply a matter of routine appointments — it is an ongoing diagnostic process driven by the absence of an integrated clinical team. Each unexplained change in behavior or health triggers multiple specialist visits, imaging, and evaluations, all of which are paid by MassHealth, Medicare, or private insurance and represent a predictable cost of the community-based model.

Hospitalizations, while variable, are a structural vulnerability of the community-based system. When clinical issues go unrecognized or untreated — or when behavioral crises escalate without on-site clinical support — individuals may experience repeated or prolonged hospital stays. These admissions are extremely costly, destabilizing, and often preventable in a bundled, clinically supervised model like ICF/IID.

In contrast, ICF/IID facilities provide on-site clinical oversight, integrated nursing, and coordinated medical and dental care, reducing unnecessary diagnostic workups, preventing delays, and avoiding many of the downstream costs created by fragmentation in a community-based system.

4. Administrative Overhead & Case Management

Administrative overhead and case management represent a significant but often invisible portion of the community-based cost structure. Unlike the ICF/IID model , where administration, clinical oversight, and case management are centralized and bundled, the community-based system distributes these functions across multiple agencies, each with its own staffing, billing, and reporting requirements. This fragmentation increases administrative workload, creates duplication, and drives up costs for MassHealth, DDS, other state agencies, and families.

High-acuity individuals require more intensive case management than the general HCBS population. They generate more incident reports, more ISP modifications, more provider communication, more crisis planning, and more coordination across medical, behavioral, and residential systems. These activities are essential for safety and stability, but they are rarely captured in DDS rate structures and are often underestimated in policy discussions.

Components of Administrative Overhead & Case Management

1. DDS Service Coordination

DDS service coordinators are responsible for ISP development, monitoring, incident follow-up, provider communication, and crisis planning. High-acuity individuals require more frequent contact, more ISP amendments, and more cross-system coordination.

2. MassHealth Case Management / LTSS Care Coordination

High-acuity individuals often qualify for LTSS Community Partners or other MassHealth care management programs. These programs involve:

- care plan development
- interdisciplinary team meetings
- medical coordination
- crisis response planning

3. Crisis-Related Administrative Work

Even when a crisis does not result in hospitalization, administrative work increases:

- incident reports
- safety plans
- staffing adjustments

- communication with clinicians
- follow-up monitoring

These costs are real and borne by multiple agencies.

Administrative Overhead & Case Management Cost Breakdown

Cost Category	Gross Cost	FMAP-Eligible?	FMAP-Adjusted Cost
DDS Service Coordination	~$6,000/year	✅ Yes	~$3,000
MassHealth Case Management / LTSS Care Coordination	~$6,000/year	✅ Yes	~$3,000
Crisis-Related Administrative Work	~$4,000/year	✅ Yes	~$2,000

Total Estimated Gross Cost:

~$16,000/year

Total Estimated FMAP-Adjusted Cost:

~$8,000/year

These estimates are conservative and reflect only system-side administrative costs, not the substantial unpaid administrative labor performed by families.

Methodology for Administrative Overhead & Case Management Estimates

DDS Service Coordination

The estimate of $6,000 per year is based on typical DDS caseload ratios and the increased time required for high-acuity individuals. Service coordinators spend more time on ISP development, incident follow-up, provider communication, and crisis planning. Using conservative assumptions about time allocation and salary/benefit costs yields an annual estimate of approximately $6,000 per individual.

MassHealth Case Management / LTSS Care Coordination

The estimate of $6,000 per year is based on the cost of LTSS Community Partners and similar MassHealth care management programs. These programs involve care plan development, interdisciplinary team meetings, medical coordination, and crisis response planning. High-acuity individuals require more frequent contact and more complex coordination, making $6,000 a conservative estimate.

Crisis-Related Administrative Work

The estimate of $4,000 per year reflects the administrative workload associated with behavioral or medical incidents that do not result in hospitalization. This includes incident reporting, safety plan development, staffing adjustments, communication with clinicians, and follow-up monitoring. High-acuity individuals generate more incidents and require more intensive administrative oversight, making this estimate conservative.

Key Insight

Administrative overhead and case management costs are often overlooked in HCBS cost analyses, yet they represent a substantial portion of the true cost of supporting high-acuity individuals. Fragmentation across DDS, MassHealth, provider agencies, and clinical systems creates duplication, inefficiency, and increased administrative burden. In contrast, ICF/IID settings centralize administration and case management, reducing duplication and improving coordination. The HCBS model shifts much of this administrative burden onto families, who perform substantial unpaid labor that is not captured in state budgets.

5. Emergency Systems (Police, MCI, ER)

Emergency services represent one of the most visible and costly points of system failure in the community-based model for high-acuity, non-verbal adults. Because group homes do not provide on-site clinical assessment and staff are not medically trained to distinguish behavioral changes from medical crises, 911 becomes the default response to a wide range of situations - from gastrointestinal pain to behavioral escalation to medication side effects. For individuals who cannot self-report symptoms, even minor changes in presentation often trigger ambulance transport and emergency department evaluation.

This reliance on emergency services is not an anomaly or a sign of poor practice; it is a structural feature of the community-based model. In the absence of integrated clinical oversight, emergency departments become the de facto diagnostic and stabilization sites for this population. As a result, high-acuity individuals experience predictable patterns of ambulance utilization, emergency department visits, extended observation, and psychiatric boarding. These events generate substantial taxpayer costs through MassHealth reimbursement and municipal EMS spending.

In contrast, ICF/IID settings provide on-site nursing, clinical triage, and coordinated medical oversight, reducing unnecessary emergency transports and preventing many crises from escalating to the point of requiring 911 activation. The emergency services costs presented here reflect the structural vulnerabilities of the community-based model rather than individual provider performance. Massachusetts-specific data show that

ambulance transports alone typically cost $400–$2,000 per trip, depending on whether the transport is Basic Life Support (BLS) or Advanced Life Support (ALS).

Components of Emergency Services Costs

Ambulance Transports (BLS and ALS)

- High-acuity individuals are almost always transported via Advanced Life Support (ALS) due to behavioral dysregulation, inability to self-report symptoms, and the need for continuous monitoring.
- ALS transports in Massachusetts typically cost hundreds to thousands of dollars per trip, depending on distance and services provided.

Emergency Department Visits

- ED visits for non-verbal, medically complex adults often require:
- extended observation
- multiple imaging studies
- sedation for evaluation
- psychiatric assessment
- These factors significantly increase costs compared to standard ED visits.

ED Boarding / Extended Observation

- When no safe discharge setting exists , such as during staffing failures or behavioral crises , individuals may remain in the ED for hours, days, or even longer.
- Extended ED stays are extremely costly and fully taxpayer-funded.

Police / EMS Co-Response

- Behavioral crises often trigger police or EMS co-response.
- These costs fall on municipal budgets, not DDS, but are still taxpayer costs

Emergency Service	Typical Frequency (High-Acuity)	Cost per Event	Annual Cost Estimate
Ambulance Transport (ALS)	2–4 per year	several hundred to several thousand dollars	varies by utilization
Emergency Department Visit	2–4 per year	varies based on imaging, sedation, and observation	varies by utilization
ED Boarding / Extended Observation	0–2 per year	substantial daily cost	varies widely
Municipal EMS / Police Co-Response	1–3 per year	municipal cost	Not Medicaid-billable

For high-acuity individuals in HCBS group homes, a predictable pattern[22] is:

- 2–4 ambulance transports per year
- 2–4 ED visits per year
- 0–2 ED boarding episodes per year

Based on typical utilization patterns, emergency services for a high-acuity individual in HCBS settings generate an estimated **$5,000–$40,000** per year in taxpayer costs, depending on frequency of ambulance transports, emergency department visits, and extended ED boarding.

Key Insight

The community-based system is designed for community living, not clinical stabilization. For high-acuity individuals who cannot self-report symptoms and require continuous clinical oversight, this structural limitation creates a predictable pattern of emergency-driven care. Group homes do not have on-site nursing, medical triage, or clinical assessment capacity, so even minor changes in behavior or presentation often trigger 911 activation, ambulance transport, and emergency department evaluation. These events are not anomalies or signs of poor practice. They are the logical outcome of placing medically complex individuals in a model built for community integration rather than medical stabilization. As a result, emergency services become the de facto clinical safety net, generating substantial taxpayer costs through MassHealth and municipal EMS systems that fall outside the DDS budget.

6. Transportation

Transportation in HCBS Group Homes

Transportation in HCBS group homes is not a unified service. Instead, it is a patchwork of arrangements that vary by provider, staffing levels, and the individual's needs. For high-acuity individuals, transportation is essential for:

- medical appointments
- day programs
- behavioral health services
- community access
- family visits

Yet HCBS group homes may lack:

- on-site transportation staff
- clinically trained drivers
- vehicles equipped for behavioral or medical needs
- integrated scheduling systems

As a result, transportation can be provided through:

- staff cars (common but risky)
- the group home's vehicle (if one exists)
- third-party transportation vendors
- MassHealth PT-1 medical transportation
- ad hoc arrangements when staffing is thin

Cost Drivers in HCBS Transportation

Transportation costs in HCBS are scattered across multiple funding streams:

- Staff time (often two staff required for safety)
- Mileage reimbursement
- Vendor contracts
- PT-1 medical transportation billing
- Overtime when transportation disrupts staffing ratios
- Missed appointments leading to repeat visits and additional transport

For high-acuity individuals, these costs accumulate quickly because transportation is frequent and often requires additional staffing support.

FMAP Eligibility in HCBS Transportation

Unlike ICF/IID settings, where transportation is fully embedded in the Medicaid rate and therefore fully FMAP-eligible, community-based transportation is funded through a mix of DDS contracts, provider operating budgets, staff mileage, municipal transit systems, and MassHealth PT-1.

Transportation in ICF/IID Settings

ICF/IID settings provide transportation as an integrated part of the facility's operations. This includes:

- on-site vehicles
- trained staff drivers
- nursing accompaniment when needed
- predictable scheduling
- coordination with on-site medical and dental clinics
- transportation embedded in the habilitation plan

This model reduces:

- missed appointments
- behavioral crises during transport
- reliance on PT-1
- overtime
- vendor costs
- safety risks

And because transportation is part of the facility's operating budget, the costs are contained, predictable, and not shifted to MassHealth or municipal systems.

The table below compares HCBS transportation costs, using intentionally conservative cost ranges that reflect typical patterns for high-acuity individuals.

Transportation Cost Comparison High Acuity

Transportation Component	HCBS Group Home	Included in HCBS Residential Rate?	ICF/IID	Included in ICF Rate	FMAP Eligible	Notes
Medical Appointments	Staff time + mileage + PT-1 + vendor costs	Partial	Included in facility operations	✅ Yes	✅ Yes (	HCBS costs vary widely; ICF/IID costs are contained
Day Hab Transportation	Often separate vendor contract	Partial, but rare	Integrated	✅ Yes	✅ Yes	Vendor contracts can be expensive and unreliable
Behavioral Health Visits	PT-1 or staff transport	Partial	Integrated	✅ Yes	✅ Yes	High-acuity individuals often require frequent visits
Community Outings, Family Visits	Staff transport, mileage	✅ Yes	Integrated	✅ Yes	✅ Yes	Not Medicaid covered
Employment / Volunteer Activities	Staff transport, mileage, municipal transit	Partial	Integrated	✅ Yes	✅ Yes	
Crisis Transport	Staff, vendor, EMS	Partial	Managed internally	✅ Yes	Mixed	HCBS often requires two staff
Municipal / Regional Transit	The Ride, regional transit authorities, shuttles	No	Very rarely used with high acuity	Not used	No	Costs borne by municipalities
Provider-Funded Vans (vehicle, insurance, fuel)	DDS/provider budgets	✅ Yes	Included	✅ Yes	✅ Yes	
Annual Cost Range	$8,000–$20,000 per person pre-FMAP		Included in ICF/IID rate			Conservative estimate; does not include missed appointments

HCBS Transportation Cost Breakdown for High-Acuity Individuals

Category	Examples	FMAP Eligible?	Annual Cost (Pre-FMAP)	State Share (Post-FMAP)
Medicaid-Covered Transportation	Day Habilitation transportation; PT-1 medical trips; behavioral health visits	✅ Yes	$8,000–$20,000+	$4,000–$10,000+
Non-Medicaid Transportation	Community outings; family visits; employment/volunteer trips; crisis transport; provider-funded vans; municipal transit	No	State-only costs (varies widely)	Same as pre-FMAP (no federal match)

Methodology

Transportation costs were estimated based on typical utilization patterns for high-acuity, non-verbal adults in HCBS settings. These individuals require frequent medical appointments, behavioral health visits, and day program attendance, all of which necessitate transportation. HCBS transportation costs include staff time (often two staff for safety), mileage reimbursement, PT-1 medical transportation, vendor contracts, and overtime when transportation disrupts staffing ratios. Annual estimates assume 12–24 medical appointments, regular day program attendance, and periodic behavioral health visits. In ICF/IID settings, transportation is integrated into the facility's operating budget and supported by trained staff, resulting in lower per-trip costs and fewer missed appointments.

Key Insight

Transportation for high-acuity individuals in HCBS group homes is fragmented, labor-intensive, and dependent on staff availability or third-party vendors. These costs are scattered across DDS, MassHealth, and provider budgets. In contrast, ICF/IID settings provide integrated, clinically supported transportation as part of the facility's operating model, resulting in lower per-trip costs, fewer missed appointments, and greater safety. HCBS is designed for community living, not clinical stabilization, and this structural reality shapes both the cost and reliability of transportation for medically complex individuals.

7. Public Benefits: SSI, SSDI, Section 8, and SNAP

1. SSI and SSDI: Income Treatment Differs Dramatically by Setting

HCBS Group Homes

In HCBS group homes operated by private providers, the portion of SSI or SSDI contributed by residents is typically 75 percent of their monthly benefit. This flows directly to the provider as room-and-board revenue. Because HCBS residential services are funded through state contracts rather than Medicaid, these dollars do not offset Medicaid costs and are not FMAP-eligible. Over time, this social security revenue contributes to the financial capacity of corporate providers, including the expansion of their real estate portfolios. By contrast, in state-operated ICF/IID settings, the resident's SSI or SSDI is applied to the Medicaid facility rate, reducing the state share of the rate and generating federal match. These funds ultimately support and enhance state-owned assets rather than private corporate holdings.

ICF/IID

In ICF/IID settings, SSI/SSDI is assigned to the facility as part of the Medicaid rate structure. Individuals retain only a small personal needs allowance, and the remainder offsets the Medicaid payment. Because the ICF/IID rate is a Medicaid service, the state receives FMAP on the Medicaid-covered portion of the rate. This creates a substantial fiscal advantage: the same SSI/SSDI dollars that are state-neutral in HCBS become part of a federally matched revenue stream in ICF/IID.

How SSI/SSDI Interacts With Medicaid in ICF/IID Settings

ICF/IID services are a Medicaid benefit, and the full per-diem rate paid to an ICF/IID is treated as a Medicaid service expenditure. All Medicaid service expenditures are FMAP-matchable, meaning the federal government pays its share of the cost.

Under federal rules for institutional Medicaid services, residents must contribute their income (including SSI or SSDI) toward the cost of care. This contribution is called patient liability. The facility applies the resident's SSI/SSDI to the total cost of care, and Medicaid pays the remaining amount of the Medicaid rate.

Because the remaining Medicaid payment is FMAP-matched, the resident's income effectively reduces the state share of a federally matched Medicaid rate. In other words, the SSI/SSDI does not receive FMAP directly, but it offsets the portion of the Medicaid rate that the state would otherwise have to pay, resulting in a lower state cost for ICF/IID services.

This mechanism is standard across all institutional Medicaid settings, including ICF/IID, nursing facilities, and chronic disease hospitals.

2. Section 8 and Other Rental Subsidies: Available Only in HCBS

HCBS Group Homes

Individuals in HCBS group homes may receive Section 8, MRVP, or other rental subsidies, but these programs do not reduce the state's housing costs for individuals with IDD. Instead, the individual is required to contribute roughly 75 percent of their SSI/SSDI to the provider for room and board, and the Section 8 voucher then pays the provider again for the same housing costs. This results in a duplication of payments rather than a cost offset. Because Section 8 is a federal housing program, not a Medicaid service, it does not interact with FMAP and does not reduce the state's HCBS service expenditures. We were unable to obtain the exact number of individuals served by the HCBS system who were recipients of Section 8 vouchers.

ICF/IID

Section 8 is not used in ICF/IID settings. Housing is included in the Medicaid facility rate and is therefore FMAP-matchable. This creates a structurally simpler and more predictable funding model.

3. SNAP: Available Only in HCBS

HCBS Group Homes

Individuals in HCBS often receive SNAP benefits, which help cover food expenses for their household or provider. However, SNAP does not lower the cost of HCBS services and is not FMAP-eligible. Instead, it operates as a separate federal program that helps subsidize daily living costs. It's important to recognize that SNAP might duplicate funding, since providers already receive room and board payments from individuals' social security contributions.

ICF/IID

SNAP is not used in ICF/IID settings. Food is included in the Medicaid rate and is therefore FMAP-eligible. This again creates a more integrated and federally supported funding structure.

4. Medicaid and Medicare: Present in Both Settings, but Used Differently

Medicaid

All individuals in both settings receive Medicaid, but the structure differs:

• HCBS: Medicaid covers discrete services (Day Hab, PT-1 medical transportation, behavioral health). Medicaid also pays for residential services and some transportation through community-based waivers.

• ICF/IID: The entire facility rate is a Medicaid service, and all allowable costs — including housing, food, staffing, transportation, and clinical supports are FMAP-eligible.

Medicare

Individuals receiving SSDI for 24 months qualify for Medicare. This applies equally in HCBS and ICF/IID and does not affect the cost comparison.

5. Summary Table: Public Benefits in HCBS vs. ICF/IID

Benefit	HCBS Group Home	ICF/IID	FMAP Impact
SSI / SSDI	Individual keeps only a small personal allowance; ~75% goes to provider as room & board (not FMAP-eligible	Individual keeps only a small personal needs allowance; remainder applied as patient liability to Medicaid rate	Advantage: ICF/IID (patient liability reduces state share of FMAP-matched rate)
Section 8 / MRVP(Massachusetts Rental Voucher Program.)	May be used, but does not reduce state costs; voucher payments duplicate the individual's 75% SSI/SSDI room-and-board contribution	Not used; housing included in Medicaid rate	Neutral (housing dollars), but HCBS structure creates duplicative payment
SNAP	Used in HCBS; creates duplicative payment because food is already covered by the individual's 75% SSI/SSDI contribution	Not used; food included in Medicaid rate	Neutral for FMAP, but HCBS structure creates additional taxpayer cost
Medicaid	Covers discrete services covers residential habilitative services via community-based waivers	Entire rate is Medicaid-billable	Advantage: ICF/IID
Medicare	Yes (if SSDI)	Yes	Neutral

6.Key Takeaway

Medicaid and Medicare are used by both models. We do not know the number of individuals in HCBS group homes who also receive Section 8 vouchers. Therefore, we aren't including these costs in our final cost comparison.

SNAP adds to the total taxpayer cost for HCBS residents without being offset by a parallel cost in the ICF/IID model. In Massachusetts, SNAP brought approximately $2.62 billion in benefits to about 1.1 million participants in FY 2024, implying an average benefit of roughly $2,350 per person per year (about $195 per month).For high-acuity adults in HCBS group homes who qualify for SNAP, this amount represents an additional federal cost that helps cover food expenses that would otherwise be fully state-funded in an ICF/IID setting.

Public benefits flow very differently in HCBS and ICF/IID settings. HCBS relies on a patchwork of non-Medicaid programs (Section 8, SNAP, SSI/SSDI retained by the individual), while ICF/IID integrates housing, food, staffing, and transportation into a single Medicaid-billable rate.

8. Municipal Costs

Municipal governments bear a distinct set of costs when high-acuity individuals are supported in small, scattered HCBS group homes rather than in a single, campus-based ICF/IID. These costs are rarely visible in state-level budgeting, but they are real: police, fire, EMS, code enforcement, and infrastructure all interact differently with dispersed residential programs than with a single, purpose-built facility.

Core municipal cost drivers

Police and public safety:

Scattered HCBS homes are embedded in ordinary residential neighborhoods. When there are behavioral crises, elopements, neighbor disputes, or calls related to staff turnover and instability, local police are the default responders. Each home generates its own pattern of calls, often across multiple municipalities, with no single point of coordination. By contrast, an ICF/IID concentrates high-acuity needs in one regulated setting with on-site staff, internal crisis protocols, and established relationships with a single local police department, reducing the number and dispersion of calls.

Fire and emergency response:

Group homes rely on local fire departments for alarms, medical assists, lift assists, and occasional evacuations. Each home must be served individually, often on streets not

designed for frequent emergency access. An ICF/IID campus, by contrast, is designed with fire safety, access, and evacuation in mind, and local fire services respond to a single, known site rather than to dozens of scattered addresses. Economies of scale in infrastructure and service delivery mean that serving more people in one place typically requires fewer marginal resources than serving the same number of people in many small sites.

Emergency medical services (EMS):

EMS systems are primarily funded and organized at the local level, and are often underfunded relative to demand. High-acuity HCBS homes generate EMS calls for seizures, behavioral crises, falls, aspiration events, and other emergencies. Each home is a separate source of demand on a local EMS system that must staff, equip, and dispatch ambulances accordingly. In an ICF/IID, on-site nursing, medical oversight, and internal protocols can prevent some calls and manage others without transport, concentrating unavoidable EMS use at a single, predictable location.

High-acuity HCBS homes generate a steady volume of EMS calls for seizures, aspiration events, falls, behavioral crises, elopements, and medication-related emergencies. Unlike an ICF/IID, which has on-site nursing, internal crisis protocols, and the ability to manage many events without transport.

Estimated Annual EMS Cost per HCBS Home

Annual EMS Transports	Estimated Municipal Cost
5 transports/year	~$10,000
10 transports/year	~$20,000
15 transports/year	~$30,000
20 transports/year	~$40,000

HCBS homes rely heavily on municipal EMS systems. These costs are absorbed by the local municipality, not the state, and not Medicaid.

An ICF/IID, by contrast, concentrates unavoidable EMS demand at a single, predictable location and prevents many calls through on-site clinical capacity.

Massachusetts data show that:

- Municipal ALS emergency ambulance transports typically cost over $2,000 per call
- BLS emergency transports cost approximately $334 per call

High-acuity group home calls are overwhelmingly ALS, not BLS.

Infrastructure, zoning, and service density

Infrastructure and roads:

Each HCBS home requires road access, plowing, maintenance, and, indirectly, contributes to wear and tear from staff vehicles, transportation vans, and frequent service visits. Research on municipal finance shows that infrastructure and service costs scale sublinearly with population-serving more people in fewer, more concentrated locations is generally more efficient than serving the same number in many dispersed sites. A campus-based ICF/IID leverages this dynamic: one driveway, one set of access roads, one cluster of utilities, serving many residents. Scattered HCBS homes multiply the number of locations that must be served and maintained.

Zoning, code enforcement, and local administration:

Municipalities must process zoning questions, building permits, inspections, and code enforcement for each HCBS home individually. Group homes are typically treated as residential uses under fair housing and disability law, limiting local control but not eliminating administrative workload. An ICF/IID, by contrast, is a single facility subject to a defined regulatory framework, with one set of local approvals and ongoing relationships.

Tax base and fiscal balance

Property tax and service balance:

From a municipal perspective, the fiscal question is whether the property tax and other local revenues associated with HCBS homes offset the marginal cost of serving them. Because group homes are often tax-exempt or owned by nonprofits, they may contribute little or nothing in property tax while still generating demand for police, fire, EMS, and infrastructure. By contrast, an ICF/IID campus is a single, large use that can be planned for explicitly in municipal budgeting and service deployment. Economies of scale in service provision mean that adding more residents to a single site typically requires less than a one-for-one increase in municipal resources.

Key insight

At the state level, HCBS and ICF/IID are often compared only in terms of Medicaid and state operating costs. Municipal costs are treated as background noise. In reality, the HCBS model externalizes a significant share of the practical burden to cities and towns: multiple police departments, fire services, EMS systems, and public works departments must each adapt to scattered, high-acuity homes. The ICF/IID model, by contrast, concentrates demand in a single, predictable location, allowing municipalities to plan, staff, and budget more efficiently. Any honest comparison of models must acknowledge that the

“community” model does not eliminate costs—it redistributes them downward to local government.

The HCBS model does not eliminate costs. It redistributes at least some of these costs downward to municipal governments.

A single high-acuity HCBS home can generate **$10,000–$40,000 per year** in EMS costs alone, based on Massachusetts ALS transport rates. When multiplied across dozens of homes, the municipal burden becomes substantial.

The ICF/IID model, by contrast, concentrates demand in one location, enabling municipalities to plan, staff, and budget more efficiently.

9. Development Bonds

Development Bonds and Capital Costs

The capital costs of developing and maintaining residential capacity for high-acuity individuals are often overlooked in cost comparisons between HCBS and ICF/IID models. Yet these costs are substantial, long-term, and borne almost entirely by the state. In Massachusetts, the primary mechanism for financing HCBS residential development is the **Facilities Consolidation Fund (FCF)**, a state-issued bond program that constructs, acquires, and renovates group homes for individuals transitioning from institutional settings or requiring specialized residential support.

Unlike the ICF/IID model, where capital and operational costs are bundled into a single Medicaid-reimbursable rate, HCBS capital costs are **not Medicaid-billable**. Federal Medicaid law prohibits FMAP for room and board, which includes the physical infrastructure of residential settings. As a result, the state must finance HCBS residential development entirely through its own bonding capacity, with no federal match.

1. The Facilities Consolidation Fund (FCF): How HCBS Homes Are Built

The FCF program, administered through MassDevelopment in partnership with DDS, finances:

- acquisition of residential properties
- construction of new group homes
- major renovations and accessibility modifications
- replacement of aging homes
- specialized homes for individuals with high medical or behavioral needs

These projects are funded through **state general obligation bonds**, typically repaid over 20–30 years. Providers receive the homes at no cost and operate them under contract with DDS. The state retains ownership and responsibility for capital upkeep.

Key characteristics of FCF financing

- **100% state-funded** (no FMAP)
- **Long-term debt service** obligations
- **Capital risk borne entirely by the state**
- **Homes often require replacement or major renovation every 20–30 years**
- **Providers do not carry capital costs on their balance sheets**

This structure creates a significant, ongoing fiscal obligation that is not reflected in annual HCBS operating budgets.

2. Capital Costs Under HCBS vs. ICF/IID

The financing structure differs sharply between the two models.

HCBS Group Homes

- Capital costs financed through **state bonds**
- **No federal match** for construction, acquisition, or renovation
- Fragmented development across dozens of sites
- Higher per-unit cost due to small scale and dispersed locations
- Providers operate homes without capital responsibility

ICF/IID Facilities

- Capital and operational costs are **bundled into the Medicaid rate**
- FMAP applies to the **entire cost structure**, including capital depreciation
- Economies of scale reduce per-resident capital cost
- Infrastructure is purpose-built for high-acuity care
- No need for state bonding to create or maintain capacity

This difference means that the state pays **far more** for capital development under HCBS than under ICF/IID, even before considering operational costs.

3. Fiscal Impact of Bond-Financed HCBS Development

A typical FCF home costs:

- **$800,000–$1.2 million** to acquire or construct
- **$300,000–$600,000** for major renovations

- **$1.2–$1.8 million** for specialized high-acuity homes

With a 20–30 year bond term, the state pays:

- **principal + interest**, often increasing total cost by 40–60%
- ongoing capital maintenance
- periodic replacement of aging homes

When multiplied across hundreds of homes statewide, the capital burden becomes substantial and entirely state-funded.

By contrast, an ICF/IID campus spreads capital costs across many residents and receives **federal matching funds** through the Medicaid rate structure.

4. Key Insight

HCBS residential capacity is built and maintained through state-issued debt with no federal match. ICF/IID capital costs, by contrast, are federally matched through the Medicaid rate.

This structural difference is rarely acknowledged in cost comparisons, yet it represents one of the most significant fiscal disparities between the two models. The HCBS model requires the state to assume long-term debt obligations for hundreds of small, dispersed homes, while the ICF/IID model leverages federal participation and economies of scale.

10. Comparing Costs

Total HCBS Cost (Net and Gross)

Annual Taxpayer Cost per Resident in HCBS Group Home (Intensive Behavioral Supports) Community-Based System				
Cost Category	**Gross Cost**	**FMAP-Eligible?**	**FMAP-Adjusted Cost**	**Notes**
Group Home Operations (HCBS Waiver)	$220,000–$300,000/year or more, depending on staffing ratios and clinical complexity.[23]	✅ Yes	$110,000-$150,000	24/7 staffing, behavioral supports
Day Habilitation Services	$78,000	✅ Yes	$39,000	5 days/week at ~$160/day
Medical & Dental (MassHealth)	$52,000-$113,000	✅ Yes	$26,000-$56,500	Includes behavioral health, primary care, pharmacy
Admin Overhead & Case Management	$16,000	⚠️ Partial	~$8,000	Some FMAP eligibility via Medicaid billing
Police & Emergency Services	$5,000-$40,000	❌ No	$5,000-$40,000	Local taxpayer burden
Transportation	$8000-$20,000	⚠️ Partial	$4,000-$10,000	
SNAP Benefits	$2,350	❌ No	$2,350	
Lost Municipal Property Tax	$2,000	❌ No	$2,000	Tax-exempt group home property, based on $10,000 tax for the house

Total Annual HCBS Cost per Resident

- Low Estimate: **$196,350**
- High Estimate: **$267,850**
- High Estimate (if using $300,000 per residential before FMAP): **$307,850**

ICF/IID Cost Model and the Fiscal Impact of Suppressed Census

Massachusetts operates two state-run ICF/IID campuses—Wrentham and Hogan—that historically housed more than a thousand residents. Today, only 200–300 beds are occupied. Because ICF/IID facilities have large fixed infrastructures that do not shrink when census declines, underutilization dramatically inflates the per-resident cost. The following model shows how restoring admissions and increasing census would reduce per-resident cost through economies of scale.

1. Current Underutilization

- Wrentham and Hogan once supported more than 1,000 residents.
- Today, only ~200–300 residents remain.
- Fixed costs such as staffing, utilities, buildings, and clinical infrastructure remain largely unchanged regardless of census.

This means the state is operating a large, high-acuity care system at a fraction of its intended capacity.

2. Cost Structure of ICF/IID Care

A. Fixed Base Cost

The model uses a system-wide base cost of $131 million, representing the annual cost of operating both campuses regardless of census.

B. Variable Staffing Cost

As census increases, incremental staffing is added at $48,000 per resident, representing:

- 0.5 FTE DSW/DSP (Direct Support Worker) (~$40,000)
- Additional clinical support (~$8,000)

C. FMAP (Federal Medicaid Match)

- ICF/IID services are Medicaid-funded.
- The federal government reimburses 50% of allowable costs.

D. Social Security Offset

Residents contribute approximately $1,200 per year from Social Security benefits.
In ICF/IID settings, this offsets state cost; in HCBS, it becomes provider revenue.

3. Economies of Scale: Estimated Cost per Resident at Different Census Levels

Census	System Wide Base Cost[24]	Estimated Additional Staffing Costs	Base +Incremental Staffing Costs	FMAP Reimburse-ment	Total Social Security Offset (75%)	Total Cost w additional staffing minus FMAP minus social security offset	Final Cost per Resident (After FMAP & SS)
250	$131,050,113	$0	$131,050,113	$65,525,057	$300,000	$65,225,057	$260,900
300	$131,050,113	$2,400,000	$133,450,113	$66,725,057	$360,000	$66,365,057	$221,217
400	$131,050,113	$7,200,000	$138,250,113	$69,125,057	$480,000	$68,645,057	$171,613
500	$131,050,113	$12,000,000	$143,050,113	$71,525,057	$600,000	$70,925,057	$141,850
600	$131,050,113	$16,800,000	$147,850,113	$73,925,057	$720,000	$73,205,057	$122,008
700	$131,050,113	$21,600,000	$152,650,113	$76,325,057	$840,000	$75,485,057	$107,836
800	$131,050,113	$26,400,000	$157,450,113	$78,725,057	$960,000	$77,765,057	$97,206
900	$131,050,113	$31,200,000	$162,250,113	$81,125,057	$1,080,000	$80,045,057	$88,939

4. Interpretation of the Table

The model shows:

- At 250 residents, the per-resident state cost is **$260,900**.
- At 500 residents, the cost drops to **$141,850**.
- At 900 residents, the cost falls to **$88,939**.

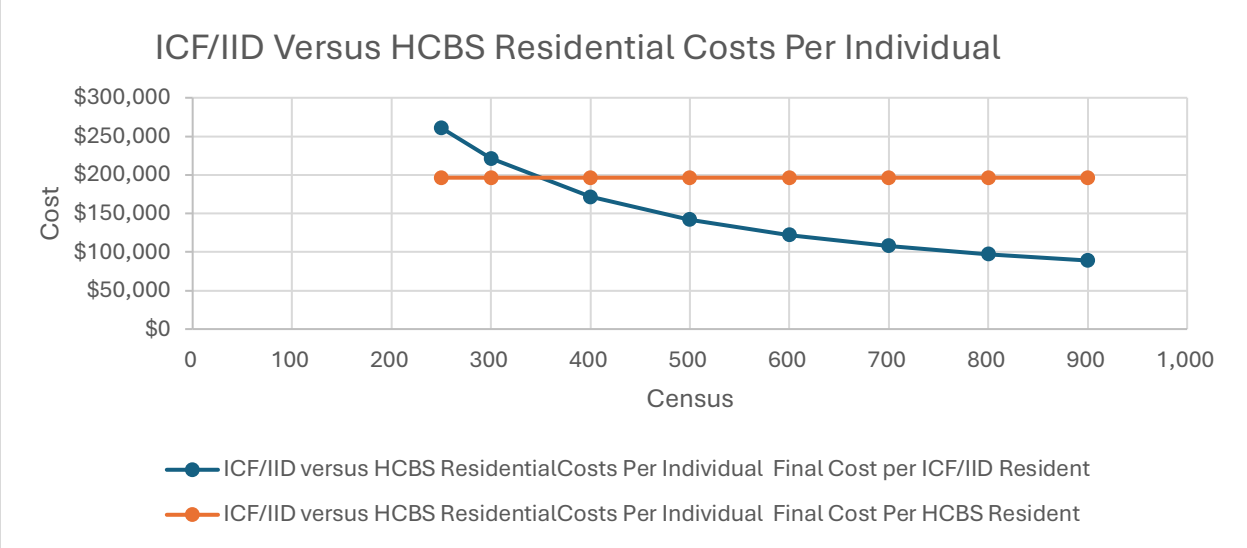
This decline occurs because the fixed base cost is spread across more residents, while FMAP and Social Security offsets scale with census.

By contrast, HCBS residential costs do not decrease with census.

Each home remains a standalone, high-cost operation.

Please note: For accuracy and transparency, it is important to note that ICF/IID campuses do not provide certain subspecialty medical services, including oncology and chemotherapy. When such needs arise, individuals receive these services in the community, funded through their health insurance. They are not included in the cost modeling presented here..

Figure X: Per-Resident Cost Comparison — ICF/IID vs. HCBS)



Lost Savings

Let's estimate how much the Commonwealth could save by increasing admissions to ICF/IID care. With a census of 400 individuals, the costs for HCBS and ICF/IID services for those with high needs are about equal. However, if the census grows to 500 (split evenly between two facilities), economies of scale make ICF/IID care less expensive. In fact, the cost difference is approximately $55,000 per person for 250 individuals, totaling a savings of $13.75 million each year. Over five years, this amounts to a savings of $68.75 million.

If both facilities operate at full capacity with 900 individuals (450 per facility), the cost advantage increases to $108,350 per person, calculated for 650 individuals. This results in annual savings just over $70 million, and over five years, around $350 million in total savings. Achieving these savings would simply require compliance with informed consent procedures and Medicaid laws that ensure patient choice.

Other Models of Care

Massachusetts offers several HCBS models beyond group homes, including self-directed services, shared living, and private congregate care. Families choose these models for many reasons, and those choices deserve respect. This report does not evaluate the appropriateness of these models for any individual; rather, it focuses on the structural and fiscal implications when the state uses these models as default placements for high-acuity individuals.

The models below are not included in the cost comparison in Part III for the following reasons.

1. Self-Directed Services

Self-direction relies heavily on natural supports and family labor. Even with provider involvement, families recruit, train, schedule, and supervise staff, and often fill staffing gaps themselves. This model can work well for some individuals, but it does not provide the 24/7 clinically supported environment required by high-acuity adults. It is therefore not comparable to either HCBS group homes or ICF/IID settings.

2. Shared Living

Shared living is a relationship-based model in which an individual lives with a caregiver or host family. It is not designed for individuals who require continuous supervision, behavioral stabilization, or complex medical care. Because the structure and staffing model differ fundamentally from both group homes and ICF/IID settings, it is not included in the cost comparison.

3. Private HCBS Congregate Care

Private congregate care is distinct from both self-direction and shared living. It is a facility-based model that provides 24/7 staffing and a structured environment, and in that sense it is more similar to ICF/IID settings. However, private congregate care may not provide:

- active treatment
- on-site nursing
- on-site medical or dental care
- interdisciplinary clinical oversight

The emphasis is typically on community integration rather than habilitation. While private congregate care may address some of the isolation and fragmentation seen in small group homes, it lacks the clinical infrastructure that defines the ICF/IID model. For this reason, it cannot be directly compared to ICF/IID settings in a cost analysis.

Why This Matters

Families may choose any of these models voluntarily, and that choice should be respected. The concern arises when the state defaults to these models , particularly self-direction or minimally staffed HCBS options, because they appear cheaper within the DDS budget. For high-acuity individuals, self-directed services often result in “empty waivers,” staffing failures, and crisis-driven medical utilization that shifts substantial costs to MassHealth, municipal EMS, and hospital systems.

These hidden taxpayer costs are outside the DDS budget but are real, significant, **and often far higher than the cost of a fully staffed residential model.**

Conclusion: Comparing HCBS vs. ICF/IID for One High-Acuity Individual

Consider a single adult with intensive behavioral needs, requiring 24/7 staffing, day habilitation, clinical oversight, and frequent emergency response. In the HCBS model, this individual lives in a small group home with high staffing ratios, receives day services five days a week, and relies on municipal EMS and police during crises. The home is tax-exempt, municipally serviced, and state-funded through a combination of waiver rates, bond-financed capital, and fragmented administrative overhead.

The total annual taxpayer cost for this individual in HCBS is approximately:

- Low estimate: $196,350
- High estimate: $267,850
- High estimate: $307,850

By contrast, the same individual placed in a state-operated ICF/IID facility benefits from bundled services, on-site clinical care, internal crisis protocols, and federally matched infrastructure. At a census of 500 residents-well within historical norms-the per-resident taxpayer cost is:

- $141,850 per year

This includes:

- Fixed infrastructure
- Incremental staffing
- FMAP reimbursement
- Social Security offset

Even at suppressed census levels (e.g., 250 residents), the ICF/IID cost remains comparable to or lower than HCBS. And unlike HCBS, ICF/IID costs decline as census rises.

Final Insight: What the Numbers Reveal

This section has demonstrated that the HCBS model, while widely embraced, is structurally more expensive for high-acuity individuals than the ICF/IID model, even under conservative assumptions. The reasons are clear:

- Capital costs are state-bonded and long-term

- Municipal services are unreimbursed and dispersed
- Per-resident costs are fixed and high, regardless of scale
- ICF/IID facilities, by contrast, leverage economies of scale, federal participation, and bundled care

The result is a system where the state pays more to deliver fragmented care in scattered homes than it would to support the same individuals in purpose-built, federally matched campuses.

The next sections offers a vision for reform, grounded in the realities we've just uncovered.

Part IV – Restoring Balance and Choice in the DDS System”

1. Economic Principles That Should Guide Policy

Economists have long recognized that large organizations benefit from economies of scale: as output increases, average cost per unit falls because fixed costs are spread across more units, labor becomes more specialized, and purchasing power increases.

ICF/IID facilities operate under these same principles. Their size allows them to:

- distribute administrative, clinical, and facility costs across many residents
- centralize specialized staff
- maintain on-site medical and behavioral expertise
- purchase goods and services in bulk

These structural efficiencies lower the per-person cost of ICF/IID care relative to small, dispersed HCBS homes, where each residence must independently replicate staffing, supervision, crisis response, and infrastructure.

A fiscally responsible system must recognize and leverage these efficiencies rather than suppress them.

2. Restoring the ICF/IID Tier as a Functional Part of the System

In two separate adjudicatory decisions (2023 and 2024), a DDS-appointed hearing officer stated that:

> *DDS avoids institutionalization at the ICFs except in cases where there is a health or safety risk to the individual or others, and generally, when all other community-based options have been exhausted*.

This reflects DDS’s own acknowledgment that the ICF/IID system is the Commonwealth’s essential safety-net for individuals whose needs cannot be met safely in community settings.

Yet despite this recognized role, Wrentham Developmental Center has not admitted a new resident in more than two years. The absence of admissions does not reflect a lack of need. It reflects administrative barriers that prevent access to a level of care the state itself deems necessary when community options fail.

If Massachusetts intends to maintain the ICF/IID level of care as a legitimate tier of support, then:

- admissions must be restored for individuals who choose this model
- the state must honor federal Medicaid law guaranteeing freedom of choice among all certified service options
- the ICF/IID tier must be stabilized so economies of scale can function
- the system must be balanced so that high-acuity needs do not overwhelm HCBS settings

A safety-net that cannot be accessed is not a safety-net.

3. What Real Choice Could Look Like

If families had genuine access to ICF/IID settings alongside HCBS options, Massachusetts could build a more balanced, transparent, and sustainable system. Real choice would allow the Commonwealth to:

- Reclaim federal funds through FMAP rather than relying almost entirely on state dollars
- Revitalize public campuses instead of leaving them underutilized
- Redirect taxpayer subsidies toward models with clear accountability and measurable outcomes
- Provide coordinated, walkable, environmentally efficient services on a single campus
- Reduce preventable emergencies, easing pressure on municipal EMS and hospital systems
- Improve HCBS quality by ensuring that private providers operate alongside a strong public benchmark

This is not an argument for placing everyone in ICF/IID care.

It is an argument for restoring choice, so individuals with high-acuity needs can access the level of care that best fits their circumstances.

A healthy system has multiple tiers, each functioning as intended.

4. Conclusion and Transition to Vision

Multiple national studies have compared HCBS and ICF/IID costs, but none have accounted for the structural differences between bundled and unbundled care models, nor

for the hidden municipal, capital, and administrative costs documented in this report. When these factors are included, the true cost of the Massachusetts DDS system across all funding streams is approximately $4.56 billion. Yet despite this enormous investment, many individuals still lack adequate services, and families continue to face "the cliff" as needs increase.

The central question is no longer whether HCBS or ICF/IID is "cheaper."

The question is:

> **What are we getting for the money we spend, and how can we build a system that delivers better outcomes, greater transparency, and real choice?**

Part V turns to that question directly. It outlines a vision for a balanced, sustainable, and person-centered system, one that restores access to the full continuum of care, strengthens HCBS, revitalizes public infrastructure, and ensures that every individual with IDD in Massachusetts can receive the level of support they need and choose.

Part V. Policy Recommendations and Vision for a Balanced, Sustainable System

Massachusetts invests billions of dollars each year in services for individuals with intellectual and developmental disabilities. Yet the system remains fragmented, financially inefficient, and unable to meet the needs of many high-acuity individuals. The analysis in Section III demonstrates that the Commonwealth's current structure, an HCBS-dominant system with an underutilized ICF/IID tier, produces high costs, inconsistent quality, and limited real choice.

A sustainable future requires a balanced continuum of care, where HCBS and ICF/IID services operate as complementary, not competing, models. The following recommendations outline a path toward a system that is fiscally responsible, clinically sound, and grounded in the rights and preferences of individuals and families.

1. Restore Access to the Full Continuum of Care

A. Reopen Admissions to ICF/IID Facilities

The ICF/IID tier cannot function as a safety-net if individuals cannot access it. Restoring admissions to Wrentham and Hogan is essential to:

- honor federal freedom-of-choice requirements
- stabilize census and restore economies of scale
- ensure that individuals with high-acuity needs have access to appropriate care
- relieve pressure on HCBS homes that are not designed for intensive behavioral or medical needs

B. Establish Clear, Transparent Criteria for Level-of-Care Determination

Families should not have to fight for access to the level of care their loved one needs. The state should adopt:

- standardized assessment tools
- transparent eligibility criteria
- an appeals process that is timely, fair, and independent

This ensures that placement decisions are based on need, not administrative preference.

2. Strengthen HCBS by Addressing Structural Weaknesses

HCBS is an essential part of the system, but it cannot succeed without reforms that address its inherent limitations.

A. Improve Oversight and Accountability

HCBS providers operate with significant autonomy and limited transparency. The state should:

- require standardized reporting of staffing levels, turnover, and incident data
- strengthen quality assurance and unannounced inspections
- ensure that public dollars are tied to measurable outcomes

B. Address the Hidden Costs of HCBS

The Commonwealth should acknowledge and plan for:

- municipal EMS and police burdens
- state-bonded capital costs
- transportation inefficiencies
- the absence of FMAP for residential operations

A transparent accounting framework will allow policymakers to compare models accurately and allocate resources responsibly.

C. Support Workforce Stability

High turnover undermines safety and continuity of care. The state should:

- develop a DSP career ladder
- expand training in behavioral and medical supports
- explore wage enhancements tied to competency and retention

3. Modernize and Revitalize Public ICF/IID Campuses

Wrentham and Hogan are valuable public assets. Rather than allowing them to decline through underutilization, the Commonwealth should invest in their renewal.

A. Create Campus-Based HCBS Options

Many states operate hybrid models, small homes located on or near ICF/IID campuses, with access to:

- on-site clinical teams

- crisis response
- day programs
- medical and dental services

This model preserves community living while leveraging campus infrastructure.

B. Develop Specialized Centers of Excellence

The campuses could serve as hubs for:

- intensive behavioral stabilization
- complex medical care
- short-term crisis placements
- training and workforce development

This strengthens the entire system, including HCBS providers.

4. Ensure Real Choice for Individuals and Families

Choice is meaningful only when all options are available.

A. Guarantee Access to All Federally Certified Options

Federal Medicaid law guarantees individuals the right to choose ICF/IID care when eligible. Massachusetts should:

- explicitly affirm this right
- ensure that service coordinators present all options neutrally
- prohibit policies that steer individuals away from ICF/IID settings

B. Provide Clear, Accessible Information

Families need accurate, unbiased information about:

- costs
- services
- staffing
- clinical supports
- crisis response
- long-term stability

This empowers informed decision-making.

5. Modernizing Placement Through Decision-Support Tools

A. Use AI Assisted Analytics for Integration and Placement

Develop a transparent, criteria-based placement system supported by modern decision-support tools, including AI-assisted analytics. As Massachusetts moves toward greater data integration across HCBS, medical, behavioral, and residential systems, AI will inevitably play a role in ensuring that referrals are clinically appropriate, equitable, and free from favoritism. The goal is not to replace human judgment, but to require DDS to follow clear, documented criteria and to create an auditable process that prevents arbitrary or opaque placement decisions.

B. Reduce Unnecessary Costs Through Modernization

AI-assisted decision-support could also reduce avoidable costs by improving placement accuracy and preventing clinically inappropriate referrals that lead to crises, hospitalizations, and emergency spending.

C. The Future of AI Assisted Decision Support Tools in Human Services

The Commonwealth should embrace AI-assisted decision-support tools. The future of health and human services will be shaped by leaders who integrate AI responsibly, transparently, and ethically — not by those who resist modernization.

6. Build a System That Works for the Next Generation

A. Need for Structural Reform

Massachusetts faces rising acuity, aging caregivers, and a workforce crisis. The current model cannot meet these challenges without structural reform.

A sustainable future requires:

- a balanced continuum where HCBS and ICF/IID complement each other
- transparent financing that reflects true costs
- public infrastructure that is fully utilized
- choice that is real, not theoretical
- care models that are clinically appropriate and fiscally responsible

B. A Vision for the Future

The recommendations above outline the structural changes needed to restore balance, transparency, and sustainability. But policy alone is not enough. Section VI turns to the

broader vision: what a modern, humane, and efficient system could look like if Massachusetts fully embraced the continuum of care, revitalized its public assets, and honored the choices of individuals and families.

This vision is not nostalgic. It is forward-looking, grounded in data, and aligned with the realities of rising acuity and fiscal responsibility. It is the path toward a system that truly works.

Part VI. Vision for the Future: A Modern, Balanced, and Sustainable System

Massachusetts stands at a crossroads. The Commonwealth invests more than $4.5 billion annually in services for individuals with intellectual and developmental disabilities, yet the system remains fragmented, inequitable, and unable to meet the needs of many families—especially those supporting individuals with high-acuity behavioral or medical challenges. The analysis in this report makes clear that the current structure is not inevitable. It is the result of policy choices, not natural constraints.

A different future is possible—one where the system is transparent, fiscally responsible, clinically effective, and respects individual and family preferences. In this future, HCBS and ICF/IID services work together as parts of an integrated care continuum.

This vision rests on five core principles.

1. A Balanced Continuum of Care

A healthy disability service system offers multiple levels of care, each functioning as intended. In this future:

- HCBS remains the backbone of community living
- ICF/IID facilities operate as specialized, high-acuity centers of excellence
- Campus-based HCBS options provide hybrid models for those who want community living with on-site clinical support
- Crisis stabilization units prevent unnecessary hospitalizations
- Families can move between levels of care as needs change

Balance, rather than uniformity, characterizes a resilient system.

2. Real Choice, Not Administrative Gatekeeping

In the future system, individuals and families can choose among all federally certified options without encountering administrative barriers or ideological steering. Service coordinators present options neutrally. Eligibility determinations are transparent. Appeals are timely and fair. And the state honors its obligation to support the level of care that best meets the individual's needs.

Choice becomes a lived reality, not a theoretical right.

3. Revitalized Public Infrastructure

Wrentham and Hogan are not relics of the past. They are public assets with enormous potential. In the future:

- Campuses are modernized, accessible, and environmentally efficient
- On-site clinics provide medical, dental, and behavioral services to both campus and community residents
- Training centers prepare the next generation of DSPs(Direct Support Professionals), nurses, and clinicians
- Campus-based HCBS homes offer community living with immediate access to specialized supports
- Public infrastructure sets a quality benchmark that elevates the entire system

Rather than being allowed to decline through underutilization, these campuses become hubs of innovation and stability.

4. A Stronger, More Stable Workforce

The future system recognizes that high-quality care depends on a skilled, supported workforce. This includes:

- A DSP career ladder with meaningful wage progression
- Specialized training in behavioral and medical supports
- Partnerships with community colleges and universities
- Retention incentives tied to competency and longevity
- On-site clinical teams that reduce burnout and turnover

A stable workforce is not a luxury—it is the foundation of safety and quality.

5. Transparent Financing and Responsible Stewardship

The future system acknowledges the true cost of care and allocates resources accordingly. This means:

- Recognizing the hidden costs of HCBS (municipal services, capital debt, transportation)

- Leveraging FMAP wherever possible
- Using public dollars to support models with measurable outcomes
- Ensuring that funding follows need, not ideology
- Making cost data publicly available and easy to understand

Fiscal responsibility and human dignity are not competing goals—they reinforce each other.

A System That Works for Everyone

In this vision, Massachusetts builds a disability service system that:

- honors individual choice
- supports families
- uses public resources wisely
- provides safe, appropriate care for high-acuity individuals
- strengthens HCBS rather than overwhelming it
- revitalizes public infrastructure
- ensures that no one falls through the cracks

This is not a return to the past. It is a forward-looking, evidence-based approach that recognizes the complexity of human needs and the responsibility of the Commonwealth to meet them.

Part VII Conclusion

Massachusetts has one of the most extensive disability service systems in the nation, yet the analysis in this report reveals a fundamental imbalance at its core. The Commonwealth relies almost exclusively on an HCBS-dominant model whose true costs are far higher than commonly understood. Capital development is financed through state bonds. Municipal services are absorbed locally. Transportation, clinical supports, and administrative overhead are fragmented across dozens of budget lines. When these hidden and unbundled costs are fully accounted for, the annual taxpayer investment in the DDS system exceeds $4.56 billion per year.

At the same time, the state's ICF/IID tier, its only fully bundled, federally matched, clinically integrated model of care-has been allowed to wither through suppressed census and administrative barriers to admission. The result is a system that pays more for less stability, more for less coordination, and more for fewer options. Families who need high-acuity care face a landscape where the most appropriate level of support is often inaccessible, despite being federally certified, historically utilized, and explicitly recognized by DDS as necessary when community options fail.

The comparison presented in Section III makes the fiscal reality unmistakable:

For individuals with intensive behavioral or medical needs, HCBS is not the cheaper model.

Even under conservative assumptions, HCBS costs exceed ICF/IID costs—sometimes by a wide margin. And unlike HCBS, ICF/IID costs decline as census rises, reflecting the economies of scale, clinical integration, and federal participation that the HCBS model cannot replicate.

But this report is not simply about cost. It is about clarity, choice, and responsibility.

Clarity, because policymakers and families deserve an honest accounting of how public dollars are spent.

Choice, because individuals have the right to access all federally certified levels of care, including ICF/IID services.

Responsibility, because the Commonwealth must steward its resources wisely while ensuring that every person—especially those with the highest needs—receives safe, appropriate, and dignified support.

The path forward is not ideological. It is practical. It is evidence-based. And it is achievable.

Massachusetts can build a system that is balanced, transparent, and sustainable. A system where HCBS thrives, not because it is the only option, but because it operates alongside a revitalized public tier that provides stability, clinical depth, and genuine choice. A system where families no longer fear "the cliff," where high-acuity individuals are not left to cycle through emergency rooms, and where public campuses are renewed rather than abandoned.

The Commonwealth has the infrastructure. It has the workforce. It has the federal framework.

What remains is the will to act.

The vision outlined in Section VI offers a blueprint for a modern, humane, and fiscally responsible continuum of care, one that honors the dignity of individuals with IDD and the trust of the taxpayers who support them. The opportunity is before us. The need is urgent. And the benefits of reform will be felt for generations.

This is the moment to build a system that truly works.

Sources and Methodology

This report draws on a combination of publicly available data, government publications, actuarial estimates, and firsthand accounts from families and professionals within the Massachusetts IDD system. All figures are either directly cited from official sources or modeled using conservative assumptions based on known parameters. Where formal data is lacking, we have clearly noted the use of anecdotal evidence or artificial intelligence modeling.

Methodological Limitations

This analysis relies on the best available public data from DDS, MassHealth, Social Security, HUD, USDA, municipal records, and national research on IDD service utilization. However, several limitations should be noted. First, Massachusetts does not publish a unified dataset that captures all funding streams supporting individuals with IDD, requiring cross-agency synthesis and conservative modeling. Second, medical and dental cost estimates exclude private insurance claims, Medicare billing, and out-of-pocket spending, meaning actual costs are likely higher than reported. Third, population estimates for acuity levels are based on DDS and RISP profiles, which do not always align with MassHealth utilization categories. Finally, because corporate provider financials and real estate holdings are not fully transparent, some off-budget costs-particularly related to property, executive compensation, and donations-may be understated. These limitations do not alter the overall conclusions but indicate that the true taxpayer cost of HCBS is likely greater than the figures presented here.

Primary Data Sources

Massachusetts Department of Developmental Services (DDS)

– Budget documents, RISP Statewide Profiles, Turning 22 reports

– Contracted provider census and rate structures

MassHealth / Executive Office of Health and Human Services (EOHHS)

– Day habilitation rate manuals and enrollment data

– Medicaid reimbursement schedules and FMAP guidelines

Social Security Administration (SSA)

– SSI/SSDI benefit averages and representative payee policies

U.S. Department of Housing and Urban Development (HUD)

– Section 8 voucher rules and average subsidy levels

U.S. Department of Agriculture (USDA)

– SNAP benefit calculations and eligibility criteria

MassDevelopment / Massachusetts Development Finance Agency

– Bond issuances for nonprofit human service providers

– Tax-exempt financing structures and interest rate savings

Municipal Tax Records and Zillow Estimates

– Property valuation and average tax rates for residential homes

Calculating HCBS Transportation Costs Using AI Modeling

-Per-Ride and Per-Mile Cost Benchmarks.

Reviewed published state and national transportation cost studies to identify average per-ride and per-mile costs for NEMT, day habilitation transportation, and community-based van services. These benchmarks were used as the basis for calculating unit costs.

- Utilization Data.

Incorporated MassHealth PT-1 utilization reports and provider-reported transportation volumes to estimate the number of annual rides associated with day habilitation attendance, routine medical appointments, and community participation for adults served in HCBS settings.

- Provider Cost Reports.

Examined provider-reported expenses for agency-operated vans, including staffing, fuel, maintenance, insurance, and contracted transportation services. These data were used to validate the reasonableness of the benchmark-based estimates.

- Conservative Assumptions.

To avoid overstating costs, high-cost outliers are excluded such as long-distance specialty trips, and transportation associated with crisis services. Assumed only

regular, recurring transportation needs and applied mid-range cost estimates rather than upper-bound figures.

Council on Quality and Leadership (CQL)

– Transportation cost studies and service utilization reports

Beacon Hill Institute Report (1992):

1992 Boston Globe Article Referencing a Beacon Hill Institute Report

– Historical analysis of privatization and cost-effectiveness in Massachusetts IDD services

Referenced in January 31, 1992 Boston Globe article discussing cost-effectiveness in Massachusetts IDD services. The original report could not be located despite extensive efforts. Its inclusion here is based on secondary citation only. We welcome access to the full report for future editions.

Although published in 1992, the Beacon Hill Institute's analysis is relevant becaus e it accurately predicted the long-term fiscal consequences of shifting from state-operated ICF/IID care to privatized HCBS services. The cost-shifting, fragmentation, and off-budget expenditures identified in the report have since materialized, making it an important historical reference point for understanding today's system.

Ricci v. Okin Consent Decree and Judge Tauro's rulings

– Federal oversight of institutional care reforms and standards

Walsh, Kastner, & Green (2003)

– Peer-reviewed cost comparison of community vs. institutional settings by severity level

The Arc of Massachusetts, MDDC, and COFAR

– Workforce data, policy briefs, and advocacy reports

BEACON HILL REPORT

Note: This report references a 1992 Beacon Hill Institute analysis cited in a historical Boston Globe article. Despite outreach and archival searches, we were unable to obtain the original document. We include this reference to acknowledge its influence on public discourse at the time, while inviting further documentation or access from readers who may have retained a copy.

Modeled Estimates

Where direct figures were unavailable, we used AI-assisted modeling based on:

- Population estimates from DDS and MassHealth
- Published rate structures and service utilization patterns
- Conservative assumptions to avoid overstatement

These modeled estimates are clearly marked and intended to provoke further inquiry, not to serve as definitive financial audits.

Anecdotal Evidence

Select sections include quotes and observations from families, frontline staff, and advocates. These are used to illustrate systemic patterns and lived experiences that are not captured in formal datasets. We welcome further data collection to validate and expand upon these insights. 1993 memorandum opinion in the case Ricci v. Okin, 823 F. Supp. 984 (D. Mass. 1993).

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[1] Code of Federal Standards, Title 42

[2] Tauro, Judge Joseph L., 1993 memorandum opinion in the case *Ricci v. Okin*, 823 F. Supp. 984 (D. Mass. 1993).

[3] Walsh, Kevin K, Kastner, Theodore A. and Green, Regina Gentlesk, Mental Retardation, April 2003, VOLUME 41, NUMBER 2: 103–122, *Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research*

[4] RISP Statewide Profiles for FY 2023

[5] Sources: MassHealth Day Habilitation Manual and rate regulations via EOHHS.

[6] Sources:www.commonwealthcarealliance.org; thearcofmass.org

[7] MassHealth Day Habilitation Manual

[8] ICF/IID care includes some on campus medical care, but does not include surgery, hospitalizations, emergency room visits, specialty diagnostics, and specialty consults. These are usually billed separately to Medicaid or Medicare;

[9] Artificial intelligence modeled these costs by examining MassHealth Coverage and Services, MassHealth Budget and Actuarial Data, and population estimates. These data are most likely an underreport because it leaves out private insurance claims, Medicare claims, and out-of-pocket expenses

[10] RISP Statewide Profiles for FY 2023

[11] All data used to estimate transportation costs were drawn from publicly available sources. These included MassHealth PT-1 utilization reports, non-emergency medical transportation (NEMT) rate schedules, published state and national transportation cost studies, and publicly filed provider cost reports. We also relied on MassHealth and DDS program descriptions, regulations, and service manuals that outline billing rules for day habilitation and associated transportation. The $33.6 million estimate reflects a synthesis of these publicly accessible data sources using a conservative methodology designed to capture only routine, recurring transportation needs.

[12] Estimated via AI review of Massachusetts Development Finance Agency (MassDevelopment) bond issuances from 2018–2023 for nonprofit human service providers.

[13] Zillow estimates

[14] Summers, John, The Group Home Racket: How Financial Model Masquerades As Human Services, Dollars and Sense, November 1, 2021

[15] Mass.gov, MDDC Fact Sheet
[16] Mass.gov, MDDC Fact Sheet; Workforce Initiative, The Arc of Massachusetts
[17] MDDC Policy Spotlight: Direct Care Workforce, June 2025
[18] Workforce Crisis: Direct Support Workforce, The Arc of Massachusetts
[19] 2025 Annual Report, National Council on Severe Autism
[20] Our Alliance has received consistent, credible reports from families and advocates indicating that required allied health services are not being provided at day habilitation sites, despite ongoing MassHealth billing; 130 CMR 419.416 and MassHealth Day Habilitation Manual require services like OT, PT, and speech therapy to be available based on individual need.
[21] https://www.ama-assn.org/about/ama-research/trends-health-care-spending
[22] MACPAC – "Spending and Utilization for Medicaid Home- and Community-Based Services" (July 2025) https://www.macpac.gov/wp-content/uploads/2025/07/Spending-and-Utilization-for-Medicaid-Home-and-Community-Based-Services.pdf
[23] AI Modeled estimate based on based on DDS and MassDevelopment Housing Guidelines
The Facilities Consolidation Fund (FCF) Program Design and Cost Guide
[24] https://budget.digital.mass.gov/summary/fy26/enacted/health-and-human-services/developmental-services/?tab=budget-tracking