THE FAMILY IS THE PMO

Program Governance for a Lifetime of Autism Care

Why raising an autistic child is the most demanding program management assignment most people will ever hold — and what the discipline of program governance owes to the families doing it without support

Avishek (Avi) Chaudhury, MBA, PMP, PROSI, CSM, SAFe,

Founder & Executive Director, The Living Autism Foundation

Principal, Sprezza Advisory

July 2026

Executive Summary

Every discipline eventually meets the place where it matters most. For project and program management, I believe that place is not a transit megaproject, a cloud migration, or an ERP rollout. It is a kitchen table, late at night, where a parent is trying to coordinate five providers, three funding streams, two systems that refuse to share information, and one child whose developmental window will not wait.

This paper makes a simple argument with uncomfortable implications:

- Families raising autistic children are already running complex, multi-decade programs.
- They manage vendors, budgets, schedules, risks, stakeholders, and benefits realization across a fragmented service landscape — performing nearly every function of an enterprise Program Management Office (PMO), without the mandate, tools, training, or institutional support that any organization would consider the bare minimum for a program a fraction of this size.

The argument rests on three claims:

- First, that the caregiving role is structurally — not metaphorically — a program management role, and that recognizing this reframes 'parent burnout' as a predictable governance failure rather than a personal one.
- Second, that the core instruments of program governance can be translated into lightweight, humane tools that give families back control: a charter, a governance cadence, a risk log, a stakeholder map, a benefits plan, stage gates, and a continuity plan. I call this translated toolkit the **Family Program Office (FPO).**
- Third, that service systems and funders must redesign around this reality. In Ontario alone, tens of thousands of children are waiting years for core autism services; every year of systemic delay transfers the full weight of program integration onto families. When the system fails to govern, the family becomes the governance layer by default — unpaid, untrained, and alone.

- ***Table 1. The Invisible PMO — enterprise functions and their family equivalents***

PMO function	What the enterprise version looks like	What the family version looks like
Intake and demand management	Standardized project intake forms, triage, and prioritization committees	Registering for diagnostic hubs, funding programs, therapy waitlists, and school assessments

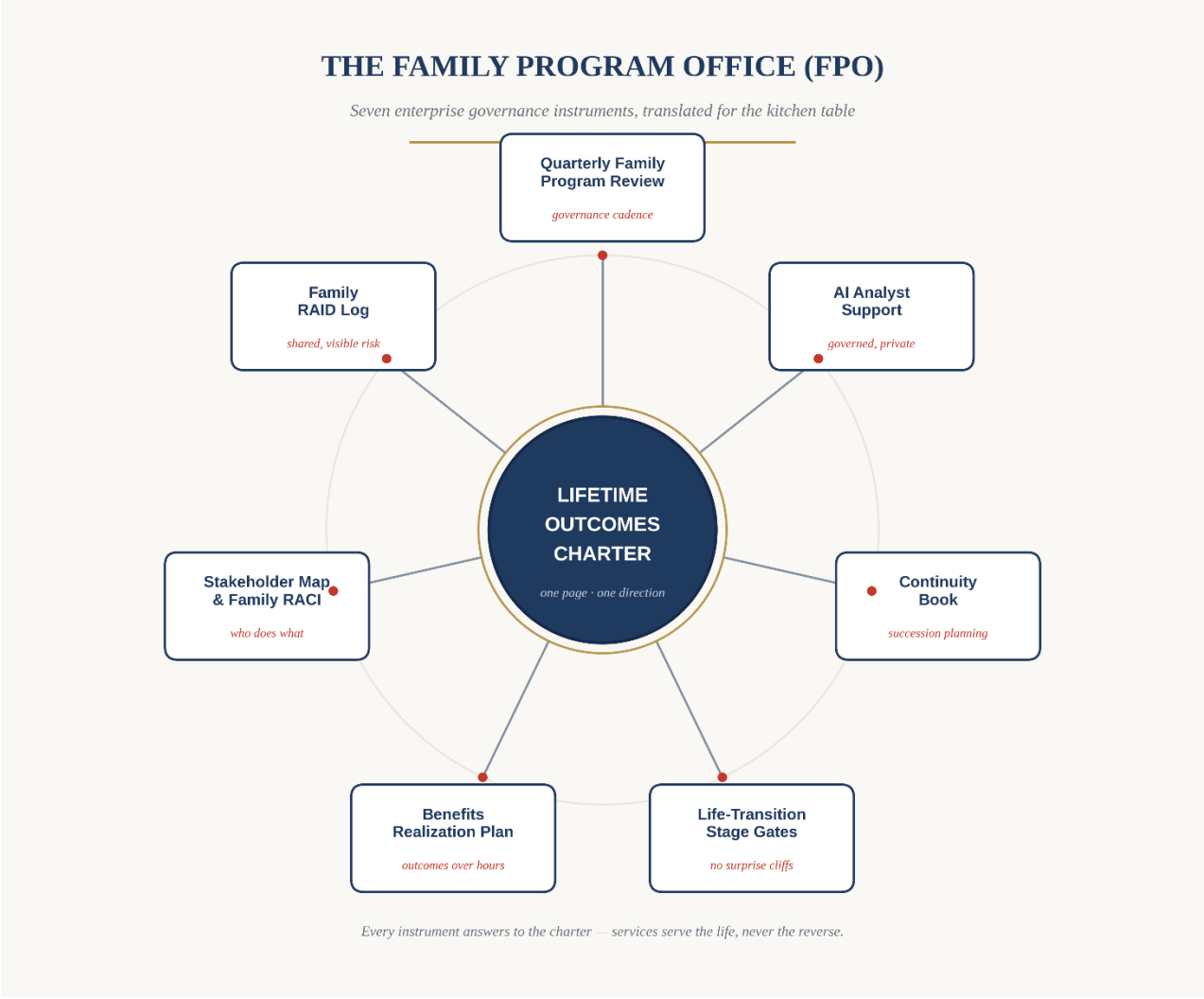
		— each with its own forms, criteria, and queues
Vendor and contract management	Procurement, SLAs, performance reviews, contract renewals	Selecting and coordinating behaviour analysts, speech-language pathologists, occupational therapists, respite workers, and tutors — often under different funding rules
Schedule management	Integrated master schedules, dependency mapping, critical path analysis	A weekly calendar where one cancelled therapy session cascades into missed school supports, lost funding hours, and parental leave from work
Financial management	Budgeting, forecasting, invoice reconciliation, variance reporting	Tracking funding agreements, out-of-pocket costs, receipts for reimbursement, and expiry dates on allocations that do not roll over
Document control	Central repositories, version control, single source of truth	Binders and inboxes holding diagnostic reports, IEPs, consent forms, and assessments — repeatedly re-submitted to systems that do not talk to each other
Stakeholder management	Stakeholder registers, communication plans, escalation paths	Managing relationships across educators, clinicians, funders, extended family, and employers — each holding a partial picture of one child
Risk management	RAID logs, mitigation plans, contingency reserves	Anticipating regression, staff turnover, funding gaps, school transitions, and crises — usually carried in one parent's head at 2 a.m.
Benefits realization	Outcome tracking against the business case	Asking the hardest question of all: is any of this actually helping my child build a good life?

I write this as both a program management professional who has spent years building PMOs across transit, healthcare, and government, and as the father of two autistic sons. I have run governance for capital programs measured in billions of dollars.

Nothing I have governed professionally is harder than what my wife and I govern at home.

This paper is an attempt to bring those two worlds into one room — and to offer families, providers, and policymakers a shared language for fixing what is broken.

Image 1: The Family Program Office



1. The Program Nobody Chartered

In enterprise program management, no serious initiative begins without a charter. The charter names the program, defines what success looks like, identifies a sponsor with authority, and grants the program manager a mandate.

It is the founding act of governance: *before we spend a dollar or assign a person, we agree on why this exists and who is responsible.*

No family receives a charter with an autism diagnosis.

What they receive instead is a report — often after a wait of months or years — and a list of recommendations that instantly becomes their problem to operationalize. From that moment, a program has begun. It has a time horizon measured in decades. It has a budget assembled from public funding, private insurance, and family savings. It has a supplier ecosystem of clinicians, therapists, educators, and support workers, each with their own intake processes, waitlists, and reporting formats.

It has hard dependencies:

- therapy hours depend on funding approvals.
- school supports depend on assessments.
- assessments depend on referrals.
- and referrals depend on a family doctor who may or may not understand autism.

And it has one — exactly one — integration function holding it all together: the parents.

I know this program intimately, because I am running it:

- By day, I lead PMO governance for one of the largest transit expansion portfolios in North America. I sit in steering committees, enforce stage gates, challenge risk registers, and brief executives on portfolio health.
- By night, I run a second program with none of that scaffolding: no steering committee, no analyst support, no escalation path, and no sponsor with the authority to remove roadblocks. The professional program has hundreds of trained people and a governance framework refined over decades. The family program has two exhausted adults and a shared calendar.

For years I treated these as separate lives. The insight at the heart of this paper is that they are the same discipline — and that the discipline has been serving the wrong side of the table exclusively.

Program management has spent seventy years perfecting governance for organizations. It has never once looked at the family and recognized a peer.

> *The question that changed my thinking was simple: if a consultant reviewed my family's caregiving operation as a program, what would they find?*
> *The answer: a heroic delivery team operating with zero governance support, carrying enterprise-level complexity on personal capacity.*
> *Any auditor would classify it as a program at critical risk — sustained only by the unsustainable.*

2. Why Caregiving Is Program Management — Structurally, Not Metaphorically

Analogies are cheap, and families do not need another one. So it is worth being precise about the claim. *The Project Management Institute* defines a program as a group of related projects and activities managed in a coordinated way to obtain benefits not available from managing them individually.

Let us consider whether autism caregiving meets that definition — not poetically, but literally:

- **Multiple related projects:** Therapy, education, funding applications, medical care, respite, skill-building, and transition planning are each substantial workstreams with their own providers, timelines, and deliverables.
- **Coordinated management:** None of these workstreams succeeds in isolation. A behaviour plan that ignores the school day fails at school. A funding stream that expires mid-therapy destroys clinical continuity. The value is created — or destroyed — in the coordination.
- **Benefits, not outputs:** The program's purpose is not to consume services; it is to produce outcomes: communication, independence, safety, participation, dignity, and quality of life across a lifespan. That is a benefits realization mandate, and it is the reason families keep going.
- **A multi-decade lifecycle:** The program horizon is not a fiscal year. It runs from diagnosis through early intervention, school-age supports, adolescence, transition to adulthood, and — the part families whisper about — the years after the parents are gone. A twenty-five-year capital program is considered extraordinarily long. **This one runs fifty years or more.**

The structural match extends to the failure modes.

- Programs fail for well-documented reasons:
- unclear objectives,
- fragmented governance,
- poor information flow between parties,
- unmanaged dependencies,
- and over-reliance on key individuals.

Every one of those failure modes is endemic to the family caregiving experience — not because families are poor managers, but because families have been assigned a program without any of the conditions under which programs succeed.

This reframing matters because of what it does to the concept of caregiver burnout. In the clinical literature, burnout is treated as a psychological outcome that needs to be managed with coping strategies and, where available, respite.

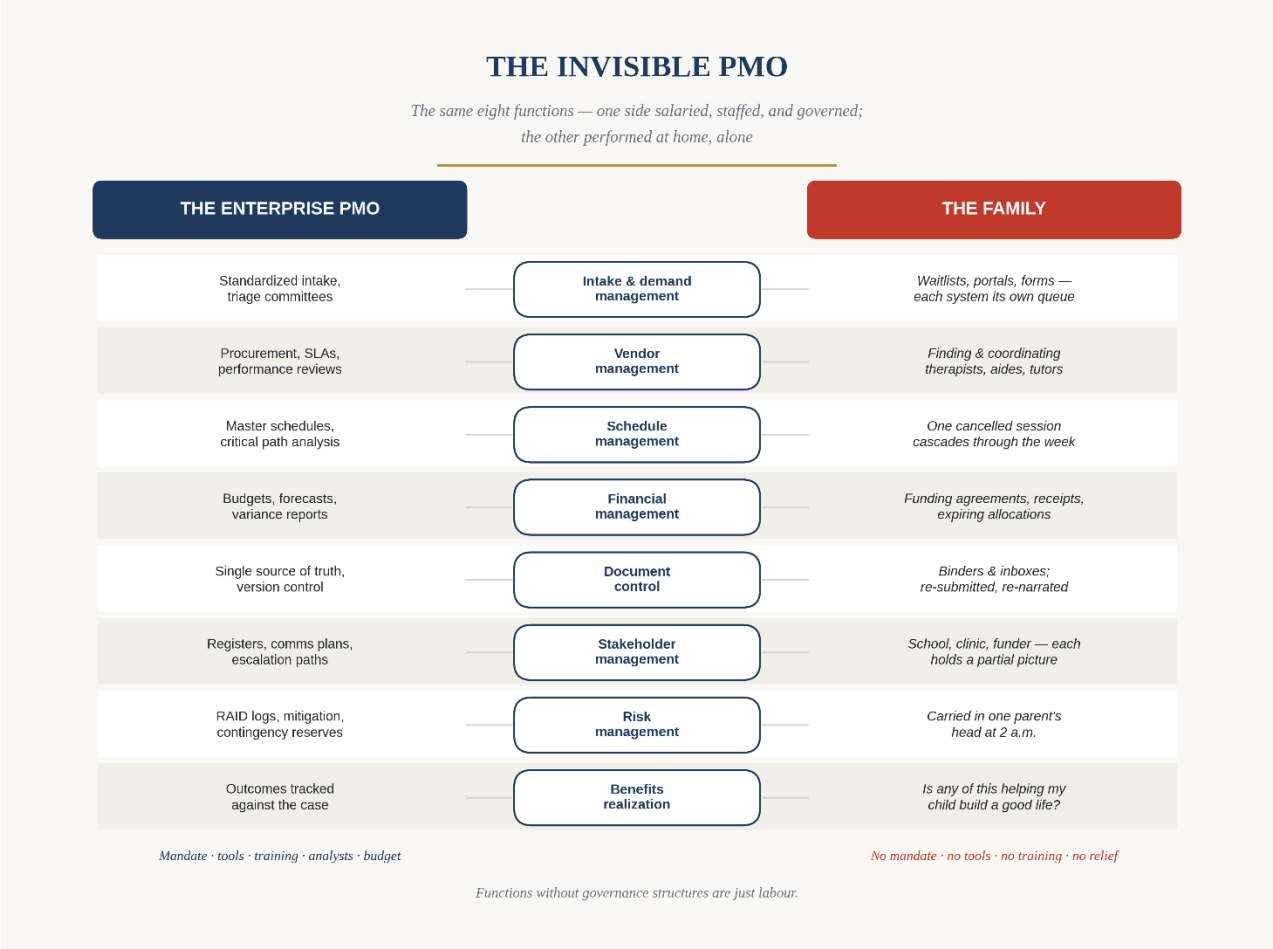
Program management offers a harder-edged diagnosis: burnout is what happens to any single-threaded resource carrying an unbounded integration load with no redundancy. We would never blame a project manager for collapsing under a portfolio that governance reviews had flagged as unstaffable.

> *We should extend families the same structural honesty. The problem is not resilience.*
>
> *The problem is design.*

3. The Invisible PMO: What Families Already Do

Before offering families anything new, the discipline should first bear witness to what they already do. Table 1 maps the standard functions of an enterprise PMO against their family equivalents. I encourage professional readers to sit with the right-hand column. Every row describes work that is currently being performed, today, by millions of families — almost always by one primary caregiver, disproportionately mothers, frequently at the cost of careers, health, and marriages.

Image 2: The Invisible PMO



Research on *'family navigation'* in the autism literature independently confirms this picture. Navigation programs — in which a trained navigator helps families identify barriers, coordinate care, and connect to community resources — exist precisely because the coordination burden is recognized as a primary driver of delayed diagnosis and unequal access. What the clinical field calls navigation, our field calls program integration. The two literatures have been describing the same missing function from opposite shores, without a bridge. This paper is an attempt to build one.

There is a second, quieter validation. The project management profession has recently begun examining neurodiversity within its own ranks, with research highlighting the strengths neurodivergent professionals bring to project work — systems thinking, pattern recognition, deep focus. ***That conversation is welcome and overdue.*** But it remains a conversation about the workplace. The larger truth is that the profession's own methods are urgently needed in the homes where neurodivergent children are growing up.

> *We have been discussing how autistic people can serve project management.*
> *We have not yet asked how project management can serve autistic people.*

4. The Governance Gap: Five Structural Failures

If families are performing PMO functions, why does the work feel less like management and more like drowning? Because functions without governance structures are just labour. Five structural gaps separate the family program from any professionally governed one.

4.1 No charter, no sponsor

The family program has no founding document and no sponsor with authority over the systems it depends on. A program sponsor's defining power is the ability to remove obstacles the program manager cannot. Families have no such figure. When the school board, the funding administrator, and the clinic disagree, there is no escalation path — only the parent, writing another email, making another call, filing another appeal. Every obstacle is removed by persistence or not at all.

4.2 A single point of failure by design

In most families, program knowledge — the history, the strategies, the contacts, the paperwork status, the subtle signals that precede a crisis — lives in one person's head. Enterprise governance treats key-person dependency as a critical risk requiring mitigation. Family caregiving institutionalizes it. The question every parent of an autistic child carries — what happens when I am gone? — is, in governance terms, a program with no succession plan and no knowledge transfer strategy, running anyway, because it has no choice.

4.3 Capacity is treated as infinite

No portfolio review would approve a resource plan in which one person works a full-time job and separately performs program integration across seven workstreams indefinitely, with no backfill and no recovery time. Yet this is the default resourcing model for autism caregiving.

> *Respite — where it exists at all — is framed as a wellness benefit rather than what it actually is: resource management for the program's only integrator.*

Systems that underfund respite are not economizing; they are running their critical resource to failure.

4.4 Information does not flow

The child's data — diagnoses, assessments, plans, progress — is scattered across school records, clinical files, funding portals, and kitchen-drawer binders. No system holds the integrated picture; therefore, **the parent is the integrated picture**. Families routinely re-narrate their child's entire history at every new intake, an experience that is both administratively wasteful and quietly dehumanizing.

> *In enterprise terms: the program has no single source of truth, and its reporting burden falls entirely on its least-resourced participant.*

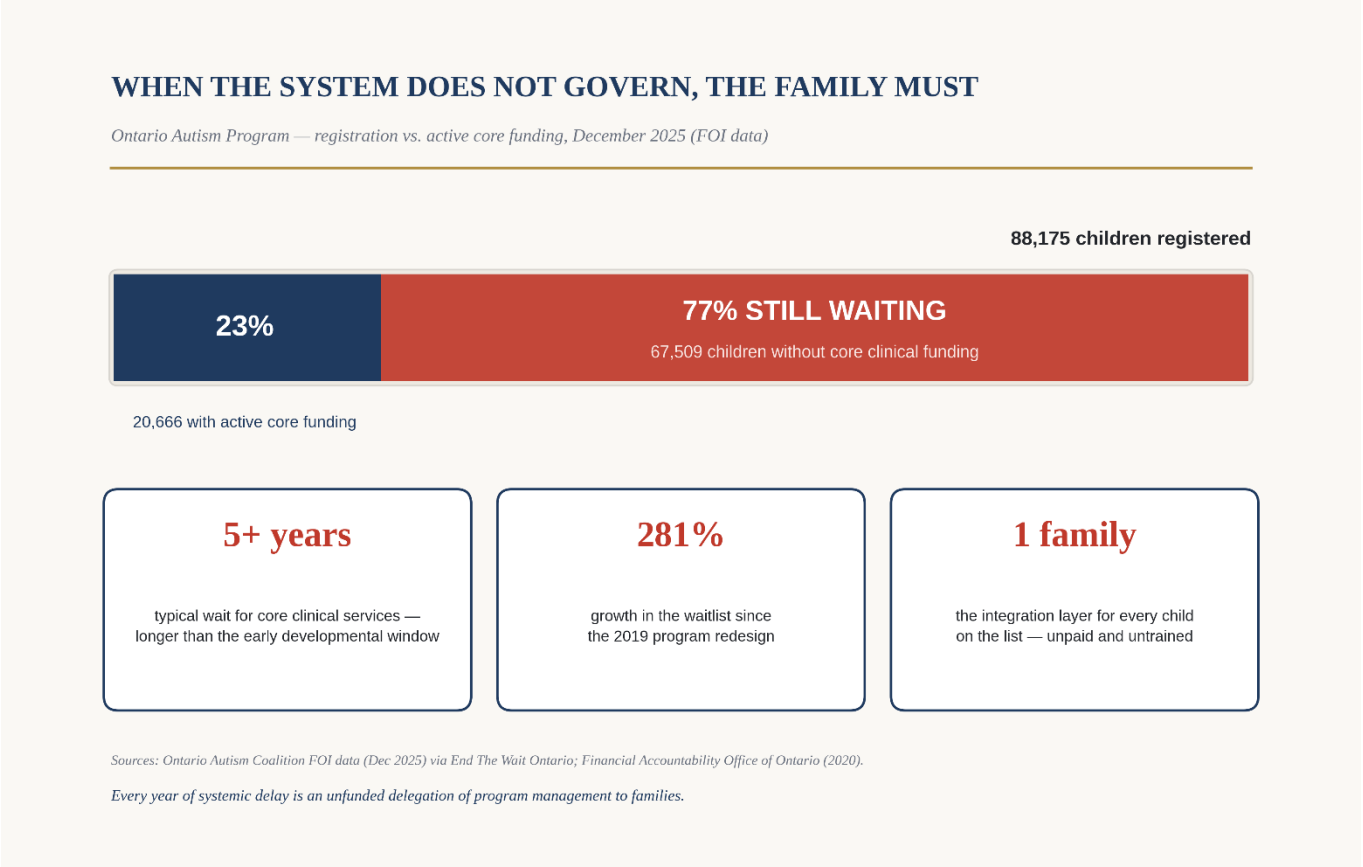
4.5 The system's delays become the family's program risk

Governance failures upstream cascade downstream and nowhere is this clearer than in the waitlists. In my home province of Ontario, freedom-of-information data from late 2025 showed roughly 87,700 children registered in the Ontario Autism Program, with only about one in four holding an active core funding agreement and typical waits for core clinical services now exceeding five years — longer than the entire early developmental window the funding is meant to serve. The province's Financial Accountability Office estimated years ago that eliminating the waitlist would require roughly double of the current allocation, and the registered population has grown dramatically since.

I cite these figures not to relitigate policy — that is the subject of this series' second paper — but to make a governance point: **every year a system fails to deliver, the integration burden it was supposed to carry is silently transferred to families.**

The waitlist is not a queue. It is an unfunded delegation of program management to the public.

Image 3: The Ontario Waitlist



5. The Family Program Office: A Translated Toolkit

The answer to the governance gap is not to hand families a copy of a standards manual and wish them luck. Enterprise instruments are heavy because enterprises can afford the weight. Families cannot.

The Family Program Office (FPO) is a deliberate act of translation: seven instruments, stripped to their essence, redesigned for a kitchen table instead of a boardroom. Each one exists to prevent a specific, predictable failure.

Table 1. The Family Program Office — seven instruments, translated

PMO instrument	Family Program Office translation	What it prevents
Program charter	A one-page Lifetime Outcomes Charter: who this child is, what a good life looks like for them, and the principles that govern every service decision	Drift — years of activity accumulating without direction, and services chosen because they were available rather than because they were right

Governance cadence	A quarterly Family Program Review: 60 minutes, both caregivers (and the child, as they grow), reviewing progress against the charter	Decision-making by exhaustion — the biggest choices of a child's life made in hallways, parking lots, and moments of crisis
RAID log	A simple living list of Risks, Assumptions, Issues, and Dependencies for the care program, reviewed at each quarterly cycle	The 2 a.m. problem — every risk stored in one caregiver's memory, invisible to everyone else until it materializes
Stakeholder register and RACI	A one-page map of every professional in the child's life and who is Responsible, Accountable, Consulted, and Informed for each domain	The coordination tax — parents acting as the only integration layer between school, clinic, and funder, repeating the same history dozens of times
Benefits realization plan	Three to five outcome measures defined by the family (communication, independence, participation, wellbeing) tracked over years, not sessions	Confusing outputs with outcomes — celebrating hours of therapy delivered while nobody asks what changed for the child
Stage gates	Planned review points at major life transitions: diagnosis, school entry, each school change, adolescence, transition to adulthood, and post-parental care	Transition cliffs — supports that end abruptly at arbitrary ages while the next system has no record the child exists
Knowledge management	A Continuity Book: the single document a stranger would need to care for this child well, updated on the same quarterly cadence	The single point of failure — the terrifying reality that if one caregiver is hospitalized tomorrow, the entire program collapses

5.1 The Lifetime Outcomes Charter

The charter is the anchor, and it is one page. It answers three questions: Who is this child — their strengths, joys, and needs, in their family's own words? What does a good life look like for them at every stage we can imagine? And what principles govern our decisions — what we will always protect, and what we will never trade away? The charter's power is not administrative; it is directional. Families under pressure are offered whatever is available, whenever it becomes available. The charter converts a reactive scramble into a criterion: does this service move us

toward the life we described, or merely fill a slot? It is also the document that tells every new professional who this child is before the file does.

5.2 The quarterly Family Program Review

Governance is not paperwork; it is a protected moment for decisions. The FPO cadence is one hour per quarter, in which the caregivers — and progressively, the child themselves, because the ultimate aim of this program is that its beneficiary becomes its director — step out of delivery mode and ask the governance questions: What progress have we seen against the charter? What is on the risk log? What decisions are we deferring out of exhaustion? What are we doing only because we have always done it? Families who adopt even this single practice report the same shift executives do when governance matures: the difference between being run by the program and running it.

5.3 The family RAID log

A RAID log for caregiving is not a spreadsheet exercise; it is the act of moving risk out of one person's midnight vigilance and into a shared, visible artifact. Risks: our lead therapist may leave the clinic; funding renewal is due in ninety days; the school transition is eight months away. Assumptions: we are assuming the current school placement continues; we are assuming grandma can still do Tuesdays. Issues: the new medication is disrupting sleep now. Dependencies: the summer program requires the updated assessment, which requires the paediatrician referral. Writing these down does not create the anxiety — the anxiety already exists. Writing them down distributes it and turns dread into a plan.

5.4 The stakeholder map and family RACI

A one-page register of every professional in the child's life, with a simple RACI across domains: who is Responsible for speech goals, who is Accountable for the IEP, who must be Consulted before medication changes, who needs to be Informed when the behaviour plan is updated. The map does two things. Internally, it reveals gaps and overlaps — the domains where three professionals each assume another is leading. Externally, it becomes an instrument of gentle authority: a family that presents a stakeholder map to a case conference has changed its role in the room from supplicant to program manager. Professionals respond to it. I have watched it happen.

5.5 The benefits realization plan

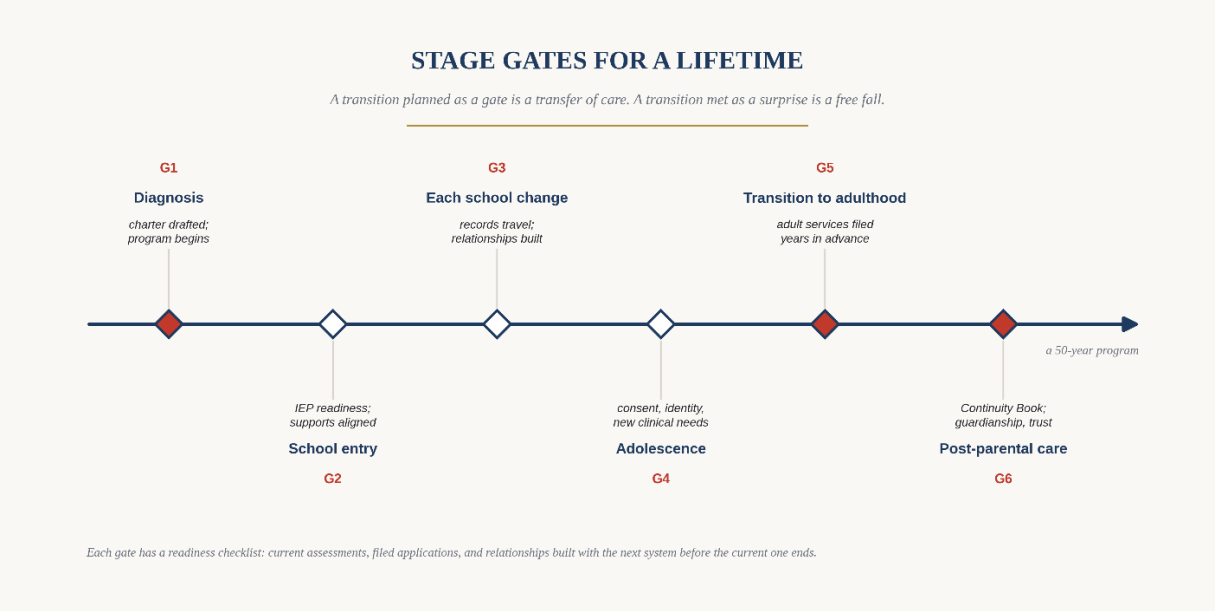
Service systems count outputs: hours delivered, sessions attended, funds disbursed. Families live for outcomes. The FPO benefits plan is three to five measures the family defines — not clinical instruments, but observable life changes: initiates communication with unfamiliar people; manages the morning routine independently; has a friend; sleeps through the night; is safe near roads. Reviewed quarterly and trended over years, these measures do what benefits realization

always does: they expose which investments are working, protect what matters from what is merely measurable, and give the family the evidence to redirect providers — or funding — when activity is not producing change.

5.6 Stage gates at life transitions

Every autism family knows the cliffs: the end of early intervention, the entry to school, the move to high school, the day paediatric services end, the eighteenth or twenty-first birthday when entire support systems evaporate by statute. Systems treat these as administrative boundaries. The FPO treats them as stage gates — known, dated, and planned for years in advance, each with its own readiness checklist: what assessments must be current, what applications must be filed, what relationships must be built with the next system before the current one ends. A transition planned as a gate is a transfer of care. A transition met as a surprise is a free fall.

Image 4: The Lifetime Stage Gates



5.7 The Continuity Book

The last instrument is the hardest to write and the most important to have. The Continuity Book is the answer to the single-point-of-failure problem: one living document containing everything a capable stranger would need to care for this child well — routines, communication methods, medical information, calming strategies, key contacts, funding logistics, and the things no file ever captures: what frightens them, what delights them, how they show you they trust you. It is succession planning for the only program where succession is guaranteed to be needed. Every family knows they should have it; almost none do, because writing it means staring directly at the fear. The FPO makes it a quarterly maintenance task instead of a monument — a page at a time, alongside the RAID log, until the unthinkable is merely documented.

6. Implications: Providers, Funders, and the Profession

A framework aimed only at families would quietly repeat the original sin — adding one more job to the people already doing too many. The FPO's real leverage is what it demands of everyone else.

For service providers

Recognize the family as the program's integration layer, and design for it. That means intake processes that ingest an existing charter and stakeholder map instead of forcing re-narration; progress reporting written against the family's outcome measures, not only clinical ones; and treating a family's quarterly review as a legitimate governance forum to which providers contribute. Navigation services, where they exist, should be understood — and funded — as PMO-as-a-service for families: not a courtesy, but core infrastructure.

For funders and policymakers

Fund the governance layer, not only the service hours. Every funding model that disburses money to families without supporting the coordination function is procuring materials for a construction site with no site manager and expressing disappointment at the result. Respite must be reframed as resource management and funded accordingly. Portals and reporting requirements should be audited for the integration burden they impose. And waitlist policy must account for the true cost of delay: every year of waiting is a year of full program load transferred to a family — a cost that is invisible in program budgets and devastating in human ones.

For the project management profession

This is the invitation I feel most personally. Our discipline holds a body of knowledge that could materially improve the lives of millions of families, and we have never systematically offered it. Imagine the professional bodies producing family-facing practice guides. Imagine chapters running pro bono FPO workshops through autism organizations, the way lawyers run legal clinics. Imagine 'caregiver program manager' recognized as professional experience on a résumé — because any hiring manager who understands what the role entails knows it outperforms most certifications. The profession has spent decades proving that governance creates value in organizations. Here is the chance to prove it creates dignity in homes.

7. A Note on AI: The Analyst the Family Never Had

Every PMO I have built or governed has run on a resource families do not have: analysts — people who consolidate information, track actions, prepare reviews, and watch dates so the decision-makers can decide. Modern AI assistants are, for the first time, making that capacity available to households: maintaining the RAID log conversationally, drafting funding applications, summarizing

assessment reports, tracking renewal dates, and preparing the quarterly review pack from a folder of documents.

As someone who writes on AI governance professionally, I offer this prospect with both enthusiasm and its necessary discipline. The family data involved is among the most sensitive that exists — a child's diagnoses, behaviours, and vulnerabilities — and the governance principles we demand of institutions apply doubly at home: privacy by default, human judgment on every consequential decision, and absolute clarity that the tool serves the charter, never the reverse.

> *Handled with that discipline, AI does not replace the family as program manager.*
> *It finally gives the program manager some staff.*

8. Conclusion: Chartering the Program

I founded **The Living Autism Foundation (Canada)** because my sons taught me that love, by itself, is not a delivery mechanism — and that the families doing the hardest work in our society do it with the least structural support. I have spent my career watching organizations invest millions in governance for programs whose failure would cost money. The programs whose failure costs a child's future run on two exhausted people and a calendar.

The thesis of this paper fits in one sentence: the family is already the PMO — the only question is whether we equip it. Equipping it costs remarkably little. A charter is a page. A review is an hour a quarter. A RAID log is a list. A Continuity Book is written a paragraph at a time. What these instruments return is not administration but authority: the transformation of a family from the exhausted object of a fragmented system into the governing intelligence of a coherent program — with a direction it chose, risks it can see, transitions it has planned for, and a story that survives any single storyteller.

To the families reading this: you have been running a program of extraordinary complexity, probably without ever being told that what you do has a name, a discipline, and a professional literature that would regard your work with awe. It does. You are not disorganized. You are under-governed — and that is fixable, starting with one page.

To my colleagues in the profession: the most important program portfolio in the world is not in any enterprise. It is distributed across millions of homes, run by unpaid program managers who never asked for the role and cannot resign from it. We know how to help. It is time we did.

> *Every program deserves a charter.*
> *Every child deserves a program that knows where it is going.*
> *And every family deserves to be recognized for what it already is: the program office holding it all together.*

Sources and Notes

- Ontario Autism Program registration and funding figures are drawn from Ontario Autism Coalition freedom-of-information data (December 2025) as compiled by End The Wait Ontario, and from reporting on the 2026 Ontario Budget allocation to the OAP.
- Historical waitlist growth and funding-need estimates are from the Financial Accountability Office of Ontario's 2020 review of autism services.
- The definition of family navigation and its core components draws on the peer-reviewed family navigation literature for autism spectrum disorder (Broder-Fingert and colleagues; Feinberg and colleagues).
- Research on neurodivergent professionals in project management refers to the Association for Project Management's 2025 study on barriers and enablers in the profession.
- Program and benefits definitions reflect Project Management Institute standards.
- All framework content — the Invisible PMO mapping and the Family Program Office — is the author's original work

About the Author

Avishek (Avi) Chaudhury, MBA, PMP, is the father of two autistic sons and the Founder and Executive Director of The Living Autism Foundation, a Canadian charitable organization supporting families living with autism.

Professionally, he is Principal of Sprezza Advisory, a boutique consultancy specializing in public sector PMO governance and AI governance and also leads PMO strategic initiatives for the City of Toronto's Transit Expansion Division, governing one of North America's largest capital programs.

He is the author of whitepapers on public sector decision intelligence and AI-enabled PMOs, and a keynote speaker on embedding AI in program governance. This paper is the first in a two-part series; the second, examining autism service systems through the lens of portfolio governance, is forthcoming.

To connect, collaborate, or bring the Family Program Office framework to your organization, reach out to Avi at **sprezzaadvisory.ca | thelivingautismfoundation.ca**