

Children with special needs

And the hidden heroes who care for them

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Executive summary

Caregivers of children with special needs are a large but often hidden segment of the workforce.¹ They include employees, managers, leaders and colleagues who may be balancing work with long-term responsibilities related to developmental, intellectual, physical, medical, behavioral health or neurodevelopmental needs.² Many don't self-identify as caregivers or may hesitate to disclose their responsibilities because of stigma, misunderstanding or concern about career consequences.³

Special needs caregiving is often intensive and complex with a long duration.⁴ It may begin early in a child's life and continue for decades.⁵ Caregivers frequently coordinate healthcare, education, insurance and public-benefit systems.⁶ These responsibilities create burdens that can affect employees' time, flexibility, financial security and career decisions.⁷

For employers, the risk is material. Caregiving demands can affect attendance, productivity, engagement, advancement and retention.⁸ Employees may reduce hours, change roles, decline promotions or leave the workforce.⁹ These outcomes can increase turnover costs and contribute to the loss of institutional knowledge.¹⁰

The employer opportunity is equally clear. Employers can support caregivers through practical, high-impact actions such as flexible scheduling and caregiver-inclusive leave practices.¹¹ Benefits navigation assistance and mental health resources can reduce caregiver burden.¹² Financial and legal planning education can strengthen long-term family resilience.¹³ Clear communication of available resources can improve benefit utilization and retention.¹⁴

Purpose of this report

This report positions special needs caregiving as a workforce strategy issue, not a niche benefits concern. Employers don't need to solve every family challenge, but they can reduce the moments of friction that force employees to choose between work, caregiving and financial stability. Organizations that act can reduce business risk while helping caregivers and their families thrive.

Caregivers of children with special needs are a large, often hidden workforce. Employers have a clear opportunity to act through practical, high-impact supports that improve employee well-being, retention, productivity and long-term financial security.

Full report

Introduction

Special needs caregiving sits at the intersection of workforce participation, benefits strategy, employee well-being and long-term financial security. Many of its workforce implications are shared across caregiving populations, including employees supporting family members with mental health conditions, cognitive decline, disabilities, chronic illness or age-related needs.

This report focuses specifically on employees caring for children with special needs because their caregiving journeys often begin early in the child's life, evolve across developmental stages and may extend into adulthood. The intent isn't to suggest that these challenges are exclusive to this population, but to examine how this particular caregiving experience intersects with benefits, career decisions and long-term financial planning.

This matters now because organizations are competing for experienced talent while also trying to manage engagement, productivity, retention and employee health costs. Employees who lack flexibility or support may make workforce decisions that are rational for their families but costly for employers.¹⁵ The business case is therefore not only compassionate, it's operational.¹⁶

The business case also includes risk prevention. A caregiver may be highly committed and highly capable yet still encounter recurring conflicts when care demands occur during work hours. Without adequate flexibility or manager support, these conflicts can turn into absenteeism, presenteeism, burnout or resignation. In many cases, the issue isn't employee commitment but a mismatch between rigid work practices and predictable caregiving realities.¹⁶

There's also a financial well-being dimension that extends across many caregiving experiences. Employees supporting children with special needs, individuals with mental health conditions, or family members experiencing cognitive decline may face significant out-of-pocket costs, reduced earning capacity and long-term planning responsibilities.¹⁷ Within that broader context, this report examines the specific financial and benefits considerations associated with caring for a child whose support needs may continue into adulthood.



Employer implication

The risk isn't just that caregiving creates stress. The risk is that unmanaged caregiving stress becomes a talent, productivity, retention and financial well-being issue.



From hidden risk to strategic opportunity

When caregiving remains invisible	When caregiving is recognized and supported
Employees struggle in silence	Employees access support earlier
Unplanned turnover increases	Retention improves
Financial stress goes unaddressed	Financial resilience strengthens
Career advancement slows	Talent pipelines remain stronger
Engagement and productivity suffer	Employees remain focused and productive
Managers react to crises	Managers plan proactively and consistently

The hidden workforce: Understanding the caregiver reality

The employee caregiver perspective

For many employees, special needs caregiving feels like managing two full-time roles simultaneously. The workday is often intertwined with therapy schedules, school communications, insurance questions, healthcare coordination and long-term planning responsibilities. Many caregivers describe constantly shifting between professional responsibilities and caregiving responsibilities, often without either role fully recognizing the demands of the other.¹⁸

Special needs caregiving covers a broad range of conditions that may affect physical, cognitive, developmental, behavioral, emotional or medical functioning.¹⁹ The population includes children with developmental and intellectual disabilities, autism spectrum disorder, physical disabilities, chronic medical conditions, behavioral health conditions, neurodevelopmental disorders, and other circumstances requiring support beyond typical childhood needs. Because diagnoses, functional abilities, resources and family circumstances vary widely, there's no single caregiving experience. However, many families share a common reality: Caregiving is intensive, nonlinear and deeply embedded in daily life.²⁰

Employees frequently worry about being perceived as less committed when they request flexibility, attend appointments or discuss caregiving responsibilities.²¹ As a result, many choose not to disclose their circumstances, creating a hidden burden that can increase stress, isolation and financial pressure while masking the true prevalence of caregiving within the workforce.²²

A defining feature of this caregiving experience is time horizon. Many caregiving journeys begin shortly after birth or diagnosis and continue through childhood, school-age years, adolescence, transition to adulthood and adult life.²³ The work changes over time. Early childhood may involve diagnosis, therapies, medical care and developmental interventions. School-age years often involve educational advocacy and service coordination. Adolescence and adulthood introduce independence, employment, housing, healthcare transition, legal planning, benefit eligibility and long-term care considerations.²⁴

The caregiver role is dynamic rather than static.²⁵ A parent may be coordinating a therapy schedule one year, negotiating school accommodations the next, and later learning about guardianship, supported decision-making, SSI, Medicaid, Achieving a Better Life Experience (ABLE) accounts, special needs trusts or housing supports.²⁶ The work rarely disappears — it evolves with the child's development, the family's resources and the systems around them.²⁶

Strengths developed through caregiving

While special needs caregiving can create significant challenges, it can also cultivate capabilities that translate directly to the workplace:

- **Complex project and schedule management**
- **Problem-solving under uncertainty**
- **Crisis management and adaptability**
- **Resource coordination and systems navigation**
- **Advocacy and persistence**
- **Relationship management and collaboration**
- **Long-term planning**
- **Resilience and resourcefulness**

These capabilities are often developed through years of coordinating care, managing competing priorities and navigating complex systems. Employers should recognize that caregivers aren't simply employees facing additional demands. They're often employees who bring valuable perspectives, capabilities and lived experience to their work.

Understanding the caregiver reality is only the first step. For employers, the more strategic question is how these daily and long-term caregiving demands translate into workforce outcomes. The next section connects the lived experience of special needs caregiving to its impact on attendance, productivity, career mobility, retention and financial security.

Visual framework: The special needs caregiving journey

Life stage	Primary caregiver focus	Common work friction	Employer support lever
Diagnosis/ early years	Diagnoses, evaluations, therapy schedules, medical care, developmental supports	Frequent appointments, uncertainty, urgent scheduling needs	Flexible scheduling, leave flexibility, Employee Assistance Program (EAP) support, care navigation
School-age years	Individualized Education Programs (IEPs), accommodations, educational advocacy, therapy, healthcare coordination	Meetings during work hours, documentation burden, crisis response	Manager guidance, protected flexibility, resource navigation, caregiver Employee Resource Group (ERG)
Adolescence/ transition	Independence skills, healthcare transition, vocational and education planning	Planning spikes, complex decisions, financial/legal stress	Financial wellness, legal referrals, transition planning education
Adulthood/ long-term support	Housing, employment support, benefits, guardianship or supported decision-making, successor care	Ongoing care coordination, future uncertainty, retention risk	Long-term planning resources, benefit education, sustained flexibility

How caregiving shapes workforce participation and financial resilience

Impact on the workforce

The previous section described what special needs caregiving looks like from the employee's perspective: intensive, evolving, often invisible and deeply embedded in daily life. Now we shift from the caregiver reality to workforce impact. The question is no longer only what caregivers manage, but how those responsibilities influence workforce participation, productivity, career mobility, retention and financial resilience.²⁷

For most employees caring for a child with special needs, the challenge is rarely a lack of commitment to work. The challenge is that caregiving responsibilities are often important, time-sensitive, recurring and difficult to control.²⁸ Appointments, therapies, school meetings, evaluations, care transitions, insurance issues and unexpected crises frequently occur during traditional business hours.²⁹ Managing multiple service systems adds additional complexity.³⁰

The workforce impact of special needs caregiving is best understood through a chain of cause and effect: Caregiving complexity creates time, focus and financial pressure; those pressures force trade-offs between work, care, income and advancement; and those trade-offs can become employer risks when they affect attendance, productivity, engagement, career mobility, retention and succession pipelines.

The hidden cost of workforce trade-offs

Many caregiving-related workforce impacts are predictable, and many are preventable. When flexibility, manager support, benefit navigation and relevant resources are available, employees are often able to navigate caregiving demands successfully. When support is absent, manageable challenges can become workforce risks.

Employees may reduce hours, decline advancement opportunities, prioritize flexibility over career progressions, seek a more flexible employer or leave the workforce.³¹ These actions are often practical family decisions rather than indications of lower ambition or commitment.³²

For employers, the consequences may include absenteeism, presenteeism, reduced engagement, weaker succession pipelines, turnover and loss of institutional knowledge. Organizations frequently experience these outcomes as talent or productivity issues even when caregiver support is part of the underlying solution.

When support is available, employees are often able to navigate caregiving demands successfully. When support is absent, manageable challenges can become workforce risks.

Common workforce tradeoffs

Caregiving pressure	Employee trade-off	Potential employer impact
Frequent appointments, therapies, school meetings, care coordination	Schedule adjustments, reduced availability	Absenteeism and workforce planning challenges
Intensive caregiving periods	Temporary withdrawal from projects or advancement opportunities	Productivity and succession planning risks
Need for flexibility and predictability	Selection of less-demanding roles	Reduced internal mobility and talent utilization
High caregiving burden³³	Job change, workforce exit	Turnover and loss of institutional knowledge
Long-term planning responsibilities	Reduced focus on career advancement	Leadership pipeline challenges

Impact on productivity and engagement

Caregiving responsibilities can affect productivity not because employees are less committed, but because they're frequently managing multiple systems simultaneously. A caregiver may be coordinating healthcare, education, insurance, public benefits, transportation, legal planning and family logistics while also meeting workplace expectations.³⁴ Even when much of this work occurs outside standard business hours, its cumulative effect can contribute to stress, fatigue, distraction and reduced capacity.

Employers may observe the symptoms — missed meetings, delayed responses, reduced engagement, increased absence or signs of burnout — before recognizing the cause. Without an understanding of caregiving as an underlying contributor, managers may respond reactively rather than proactively. Organizations that provide flexibility, planning support, resource navigation and manager education can often reduce these pressures before they become larger workforce issues.

Impact on career mobility

One of the most overlooked consequences of special needs caregiving is its effect on career progression. Beyond immediate productivity effects, caregiving responsibilities can shape long-term career trajectories. Choices that prioritize flexibility may influence advancement opportunities, income growth, retirement savings and long-term wealth accumulation. These decisions are often practical responses to caregiving realities rather than reflections of lower ambition or commitment.

Over time, these choices can affect income growth, retirement savings, Social Security credits and long-term wealth accumulation. They can also affect employer talent pipelines by reducing the number of experienced employees pursuing leadership opportunities. Organizations may interpret leadership gaps as talent shortages when flexibility and caregiver support are part of the underlying issue.

Impact on financial security

Special needs caregiving can affect both sides of a household's financial equation. Families may face substantial expenses related to therapies and medical care.³⁵ Legal planning and future support planning create additional financial demands.³⁶ Reduced work participation can limit long-term wealth accumulation.³⁷

The result is pressure on both income and expenses. Over time, caregivers may contribute less to retirement savings, postpone financial goals, reduce emergency savings or delay investments in their own long-term security. Financial stress can also become a workplace issue, affecting focus, decision-making, productivity and overall well-being.

For employers, this creates an opportunity to connect caregiver support with broader financial wellness, retirement readiness, mental health and benefits strategies rather than treating caregiving as a stand-alone issue.

The combined impact equation

The most important insight is that these pressures compound. A caregiver facing high out-of-pocket expenses may need to remain employed for income, health coverage and long-term financial stability while simultaneously needing flexibility to manage care responsibilities. If flexibility is absent, the employee may absorb increasing levels of stress until the situation becomes unsustainable. The employer then experiences the issue as burnout, disengagement, absenteeism, stalled advancement or resignation rather than as an identifiable support gap.

The goal isn't to lower expectations for caregivers. It's to reduce avoidable friction so employees can continue contributing while managing responsibilities that are central to their family's stability. When employers recognize this connection, caregiver support becomes more than a compassionate benefit — it becomes a strategy for workforce participation, retention, productivity, financial resilience and talent continuity.³⁸

Caregiver choices that prioritize flexibility may influence career advancement opportunities, income growth, retirement savings and long-term wealth accumulation. These decisions are often practical responses to caregiving realities rather than reflections of lower ambition or commitment.

From workforce risk to workforce advantage

Why employers should act

Employers should act because special needs caregiving is already shaping workforce outcomes. The choice isn't whether caregiving affects the organization, it's whether the organization recognizes and manages the impact intentionally. A supportive strategy can reduce avoidable attrition, improve engagement, support financial well-being and reinforce a culture of inclusion and trust.

Retention is one of the strongest reasons to act. Losing these experienced employees can mean losing institutional knowledge, client relationships, technical expertise and leadership potential. Supportive policies and manager practices are often less costly than replacing experienced talent.³⁹

Productivity is another reason. Caregiving responsibilities can create absenteeism and presenteeism, but these effects are often driven by rigidity rather than lack of commitment.

When employees can adjust schedules, access resources and communicate with managers without fear, they're better able to address care needs while maintaining performance. Flexibility and clarity can convert unmanaged disruption into planned coordination.⁴⁰

Employee well-being and financial resilience also matter. Special needs caregiving can intensify stress, sleep disruption, anxiety and financial strain. Employers already invest in mental health, financial wellness, retirement readiness, leave and EAP resources. Connecting those investments to caregiver realities can improve relevance and utilization.⁴¹

Finally, supporting caregivers strengthens employer brand and inclusion. Caregiver-friendly workplaces signal that employees are valued beyond narrow job output. This can be especially powerful in attracting and retaining employees who are caregivers today or who anticipate caregiving responsibilities in the future.⁴²

Employer value proposition

- **Retain** experienced employees by reducing forced trade-offs between work and care.
- **Improve** engagement by making support visible, credible and safe to use.
- **Protect** productivity by replacing ad hoc disruption with flexible planning and resource navigation.
- **Strengthen** financial wellness by connecting caregivers to long-term planning education and vetted resources.
- **Build** a more inclusive culture by normalizing caregiving as a workforce reality.



TIP

Shift from viewing special needs caregiving as an accommodation issue to recognizing it as a workforce resilience issue. The most effective organizations understand that caregiver support is about retaining talent, strengthening productivity, improving financial well-being, developing future leaders and building a stronger workforce for the future.

What works: High-impact solutions

What caregivers say they need

Across caregiving populations, employees consistently identify several themes:

- **Flexibility without stigma**⁴²
- **Managers who demonstrate understanding**⁴³
- **Easier navigation of complex systems**⁴⁴
- **Access to reliable information**
- **Support for long-term financial planning**⁴⁵
- **Confidence that utilizing available benefits won't negatively affect career opportunities**

High-impact solutions are most effective when they address these practical needs rather than adding additional complexity.⁴⁶

The strongest employer strategies combine flexibility, navigation, financial planning, manager capability and culture.⁴⁷ No single benefit will meet every need because special needs caregiving varies by diagnosis, age, family structure, financial resources, location and available community supports. The goal is to create a practical support ecosystem that reduces friction and helps employees remain productive and financially stable.⁴⁸

High-impact solutions share four characteristics: They're easy to find, safe to use, relevant to real caregiver needs and sustained over time. A benefit that employees cannot locate or fear using will have limited impact. A program designed for eldercare alone may not reflect special needs caregiving complexity. A one-time webinar may raise awareness, but it won't solve recurring navigation, manager or planning needs.

Design principles for employer action

- **Listen first.** Use confidential surveys, focus groups and caregiver ERGs to identify what employees actually need.
- **Make support easy to find.** Consolidate resources and communicate them repeatedly, not only during open enrollment.
- **Normalize use.** Leaders and managers should signal that caregiving support is legitimate, not a career liability.
- **Support the full journey.** Include early diagnosis, school-age needs, transition to adulthood and long-term financial/legal planning.
- **Measure outcomes.** Evaluate use, satisfaction, retention, absenteeism and employee feedback to refine programs.

High-impact action framework

Action	What it solves	Practical implementation	Why it matters
Flexible scheduling and work design	Appointments, emergencies, school meetings, care transitions	Offer flexible start/end times, compressed schedules, temporary adjustments, makeup time, hybrid where role-appropriate	Reduces forced trade-offs and prevents avoidable absence or resignation
Caregiver-inclusive leave practices	High-intensity caregiving events and recurring obligations	Clarify Family and Medical Leave Act (FMLA), paid leave, personal leave, intermittent leave and caregiver leave options	Gives employees confidence that care needs can be managed without job loss fear
Manager education	Stigma, inconsistency, fear of disclosure	Train managers to respond with empathy, focus on outcomes, apply policies consistently and refer to resources	Managers often determine whether formal benefits feel usable
Care navigation and resource referral	Fragmented systems and time-consuming search for support	Provide benefits guides, resource portals, specialist referrals, vendor/navigation services and EAP routing	Saves time and reduces administrative burden
Financial and special needs planning education	Long-term costs, benefit eligibility, retirement strain	Offer education on ABLE accounts, special needs trusts, public benefits, estate planning, retirement trade-offs; referrals to qualified professionals	Improves family financial security and reduces stress
Mental health and peer support	Isolation, burnout, chronic stress	Develop EAPs, counseling, peer groups, caregiver ERGs, resilience resources	Supports sustainability and helps employees feel less alone
Communication and measurement	Underutilization and lack of visibility	Implement regular benefits communication, caregiver surveys, utilization data, and retention and absence trend reviews	Ensures programs are understood, relevant and continuously improved

A workforce imperative: The leadership agenda

Employer opportunity

Special needs caregiving is a significant workforce reality.⁴⁹ Caregiving demands often persist for many years and even decades.⁵⁰ Employees frequently coordinate multiple service systems while working.⁵¹

The cost of inaction is measurable in human and business terms. Without support, caregiving pressures can undermine workforce participation, employee well-being, engagement and retention. Employers may experience corresponding impacts on productivity and talent continuity.

The employer opportunity is to make caregiving easier to manage without lowering performance expectations. That requires flexibility, clear policies, trained managers, easy-to-access resources, financial and legal planning education, mental health support, and a culture where employees feel safe asking for help. Effective support isn't about solving every family challenge. It's about removing unnecessary workplace friction so employees can continue contributing while fulfilling caregiving responsibilities.

Organizations that act now can strengthen employee well-being, support long-term financial security, improve retention and build workplaces that reflect the realities of modern families. By recognizing these hidden heroes and investing in practical support, employers can create meaningful value for caregivers, their children and the organization as a whole.

Immediate next steps for employers

- **Assess.** Identify where current benefits, leave, flexibility and financial wellness resources do or don't address special needs caregiving.
- **Listen.** Create confidential channels for caregivers to share needs and barriers without fear of stigma.
- **Simplify.** Make resources easier to find through a centralized caregiver support hub or benefits guide.
- **Equip managers.** Provide guidance on flexibility, disclosure, referrals and performance-focused support.
- **Target financial security.** Offer education and referrals for ABLE accounts, special needs trusts, public benefits, estate planning and retirement trade-offs.
- **Sustain.** Measure utilization, retention, satisfaction and feedback so caregiver support evolves with employee needs.



TIP

Treat special needs caregiving as a workforce strategy priority: Identify the caregiver population, listen to their needs, map current resources, close high-friction gaps, train managers and measure impact.

Conclusion

Call to action

Caregivers of children with special needs aren't a niche population. They're a significant and often invisible segment of today's workforce whose experiences influence talent retention, workforce participation, financial security, employee well-being and organizational performance.⁵² They're employees, managers, leaders and colleagues who balance professional responsibilities with caregiving demands that can be intensive, evolving and long term.

Throughout this report, one theme has consistently emerged: Much of the caregiving burden remains hidden. Employers rarely see the medical appointments, educational advocacy, care coordination, insurance navigation, financial planning, legal planning and long-term decision-making that occur outside the workplace. Yet the effects are often visible through workforce outcomes, including absenteeism, turnover, reduced career mobility, financial strain, burnout and declining engagement.

Special needs caregiving isn't simply a family issue, a leave issue or an accommodation issue. It's a workforce issue with implications for retention, productivity, financial well-being, workforce resilience and leadership development. Organizations that recognize and support caregivers aren't only helping employees manage complex responsibilities, they're strengthening the workforce on which their future success depends.

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Appendix A: Condition descriptions

This appendix provides deeper context on the breadth of special needs conditions while keeping the main report focused on workforce, benefits and caregiver-support strategy. The descriptions below are intended to support strategy discussions. They shouldn't be used as clinical guidance or as a substitute for advice from qualified medical, educational, legal or financial professionals.

Special needs caregiving spans a wide range of diagnoses and functional needs. Some children require targeted accommodations or intermittent support; others require intensive supervision, medical management, specialized education, mobility assistance, behavioral support or long-term services that may continue into adulthood. The caregiver experience is shaped not only by diagnosis, but also by functional capacity, family resources, community support, insurance coverage, school services and the availability of providers.⁵³

Condition area	Description	Common caregiving implications
Developmental and intellectual disabilities	Includes conditions that affect cognitive development, learning, adaptive functioning, communication, social skills or daily living skills. Examples include autism spectrum disorder, Down syndrome, cerebral palsy and intellectual disability.	Caregivers may coordinate developmental therapies, educational support, adaptive skill-building, behavioral support, transportation and long-term planning for independence, employment, housing and adult services.
Autism spectrum disorder and neurodevelopmental conditions	May involve differences in communication, social interaction, behavior, sensory processing, executive functioning and adaptive skills. Support needs vary widely across individuals and may change over time.	Families may coordinate evaluations, therapies, educational accommodations, behavioral support, sensory-informed environments, transition planning, and future financial or legal planning.
Physical disabilities and mobility-related conditions	May affect movement, strength, coordination, mobility, self-care or access to physical environments. Functional needs may range from accommodations to significant daily support.	Caregivers may manage equipment, transportation, accessibility modifications, therapies, school accommodations, personal care support, and planning for accessible housing or community participation.

Condition area	Description	Common caregiving implications
Chronic medical and complex healthcare needs	Includes conditions requiring ongoing treatment, monitoring, medication, specialist care or equipment. Examples include epilepsy, cystic fibrosis, congenital disorders and complex medical needs involving specialized providers.	Families may coordinate multiple clinicians, medication schedules, insurance authorizations, specialty appointments, emergency plans, care records, medical equipment and transitions from pediatric to adult healthcare.
Behavioral health and emotional conditions	May include behavioral health challenges, anxiety disorders, severe emotional disturbances, ADHD and other conditions that affect regulation, attention, coping, school participation or family routines.	Caregivers may coordinate behavioral health providers, school support, crisis plans, medication management, therapy appointments and workplace flexibility during periods of heightened need.
Multiple or overlapping needs	Many children have more than one diagnosis or support need, creating complex and changing combinations of medical, developmental, behavioral, educational and social considerations.	Caregivers often become the central coordinator across systems, making this one of the strongest drivers of scheduling burden, administrative work, financial strain and long-term planning needs.



The most important workforce implication is that diagnosis alone doesn't predict caregiver burden. Two employees may have children with similar labels but very different daily demands depending on level of independence, co-occurring conditions, service access, insurance coverage, school support and family circumstances. For employers, support strategies should therefore be flexible, confidential and needs-based rather than diagnosis-based.⁵⁴

Appendix B: System-by-system breakdown

Caregivers of children with special needs often interact with multiple systems that aren’t designed to operate as one coordinated experience. The report compresses this point into the caregiver

reality and employer business case. This appendix provides a fuller breakdown of the system complexity that often sits behind workplace scheduling conflicts, stress and administrative burden.⁵⁵

System	What caregivers may need to manage	Why it matters for work and financial security
Healthcare	Primary care, specialists, therapists, behavioral health providers, medication plans, referrals, authorizations, records, equipment, treatment plans and transitions from pediatric to adult care.	Appointments often occur during business hours. Coordination demands can create absence, schedule variability, cognitive load, insurance disputes and high out-of-pocket costs.
Education	Evaluations, IEPs or 504 accommodations, specialized instruction, related services, school meetings, progress monitoring, documentation, and collaboration with educators and therapists.	School meetings and service issues frequently require caregiver time during work hours. Inconsistent support can trigger crises, additional advocacy or emergency schedule changes.
Insurance and benefits	Coverage reviews, prior authorizations, claims, denials, appeals, provider networks, documentation, reimbursement, and coordination between private insurance and public programs.	Administrative burden can consume significant time and may affect family finances. Insurance limitations can increase stress and influence job decisions tied to health coverage.
Public programs	Medicaid, SSI, Medicaid waivers, state developmental disability services, vocational rehabilitation, transportation assistance, respite support, and long-term services and support.	Eligibility rules, waiting lists, income and asset limits, and state variation can make public benefits difficult to navigate and may require careful financial planning.

System	What caregivers may need to manage	Why it matters for work and financial security
Community and nonprofit support	Disease-specific organizations, advocacy groups, peer support networks, camps, recreational programs, parent-to-parent support, respite resources and local service agencies.	These resources can reduce isolation and fill service gaps. But awareness is often inconsistent, and families may rely on informal networks to find help.
Legal and transition systems	Guardianship or supported decision-making, powers of attorney, healthcare decision-making, special education transition plans, postsecondary accommodations, employment support, housing, and successor caregiving plans.	Transition planning can intensify during adolescence and young adulthood. Legal and financial decisions may affect benefits, independence, caregiver security and long-term quality of life.
Workplace	Flexible schedules, leave, EAP, mental health resources, financial wellness, caregiver navigation, ERGs, communication with managers and safe access to benefits.	Employer support can reduce friction and help caregivers remain engaged, productive and financially stable while fulfilling family responsibilities.

The cross-system burden is a primary reason that caregivers are often described as the “quarterbacks” of their child’s support system. They aren’t simply attending appointments, they’re connecting information across institutions, monitoring whether services are delivered, resolving administrative barriers, preserving records, and planning around systems that may have different rules, timelines and eligibility criteria.

For employers, this system map helps explain why practical support has value even when they cannot directly provide healthcare, education, public benefits or community services. Employers can reduce friction by providing flexibility, manager understanding, centralized resource navigation, benefits guidance, mental health support and financial planning education that helps caregivers move through these systems more efficiently.⁵⁶

Appendix C: Full financial planning explanations

Financial planning for families caring for children with special needs is a long-term security issue. Families must often balance current expenses with the future needs of the child, the caregiver’s retirement security, public-benefit eligibility, legal

protections and successor caregiving plans. This appendix expands the report’s financial security discussion and is intended as educational context, not financial, legal, tax or benefits advice.⁵⁷

Planning topic	Expanded explanation	Employer relevance
Current expense management	Families may incur recurring costs for therapies, medical care, adaptive equipment, specialized childcare, transportation, home modifications, educational support, respite care and assistive technology. Insurance and public programs may cover some expenses, but deductibles, copayments, uncovered services, out-of-network care and travel can create substantial out-of-pocket costs.	Financial strain can increase stress and affect work focus. Financial wellness programs can help employees organize budgets, understand benefits and identify credible resources.
Income and career trade-offs	Caregiving responsibilities may lead employees to reduce hours, decline promotions, choose roles based on flexibility, pause work or leave the workforce. These decisions can reduce wages, retirement contributions, Social Security credits, pension growth and long-term wealth accumulation.	Flexible work, leave options and manager support can help employees remain attached to the workforce and reduce long-term financial harm.
ABLE accounts	ABLE accounts can allow eligible individuals with disabilities to save and invest funds for qualified disability-related expenses while preserving eligibility for certain means-tested public benefits, subject to program rules and contribution limits.	Employers can offer education or resource referrals so employees understand that dedicated disability-related savings tools may exist and should be evaluated with qualified advisors.



Planning topic	Expanded explanation	Employer relevance
Special needs trusts	Special needs trusts can hold assets for a beneficiary with a disability while helping preserve eligibility for certain public benefits when structured appropriately. They may be used to fund quality-of-life expenses not covered by public programs.	Employers shouldn't provide legal advice but can connect employees to legal-plan resources, financial education or vetted professionals familiar with disability planning.
Public-benefit coordination	Programs such as SSI, Medicaid, Medicaid waivers, vocational rehabilitation and state disability services can be vital. Eligibility may depend on income, assets, disability standards, age, state rules and program requirements. Gifts, inheritances, savings and work income may affect eligibility.	Benefits education can reduce employee uncertainty and help families avoid unintended consequences. Resource navigation can be especially valuable during transition to adulthood.

Planning topic	Expanded explanation	Employer relevance
Estate planning and successor care	Plans may address wills, beneficiary designations, special needs trusts, letters of intent, successor trustees, guardianship or supported decision-making, powers of attorney, healthcare decision-making, and future care preferences.	Legal benefits, EAP referrals and financial wellness resources can help caregivers initiate planning conversations before a crisis occurs.
Caregiver financial security	Caregivers may prioritize the child's immediate needs over their own retirement, emergency savings, disability insurance, life insurance and long-term care planning. A sustainable plan should consider both the child's future and the caregiver's own financial resilience.	Employers can position retirement planning, insurance education, financial counseling and mental health support as part of caregiver sustainability.
Transition-to-adulthood planning	As children approach adulthood, families may need to evaluate healthcare transition, education or employment support, housing, transportation, benefit eligibility, decision-making authority, and long-term care arrangements.	This is a predictable high-stress period. Employers can offer transition-focused education, flexibility and resources.
Balancing current and future goals	Families often must decide how to allocate limited resources between immediate therapies and support, household needs, retirement savings, emergency savings, and future care arrangements. No single plan fits all families.	Financial wellness resources should be framed as guidance to help caregivers evaluate trade-offs, not as a one-size-fits-all solution.

Employers don't need to become financial planners, disability attorneys or public-benefits experts. The high-impact employer role is to recognize financial complexity, make relevant resources easier to find, and connect employees with qualified professionals

or educational tools. When paired with flexibility and manager support, financial planning resources can reduce stress and help employees remain productive and engaged while making long-range decisions for their families.⁵⁸

Appendix D: Caregiver resources

Here's a list of government, nonprofit, professional and selected private-sector organizations and websites that may help employees, families, benefits teams and managers locate information about special needs caregiving, public benefits, education, healthcare transition, financial planning, workplace support and caregiver well-being. Their inclusion does not constitute endorsement and is for informational purposes only. Employers should verify current URLs, eligibility rules, program availability and state-specific requirements before distributing. Resources are organized by audience and alphabetized within each section.

Employers may want to pair this list with internal benefits information, EAP contact details, health plan care-navigation contacts, legal-plan resources, financial wellness resources, leave and flexibility policies, and a plain-language note encouraging employees to contact HR or a benefits representative for confidential guidance.

Federal government resources

Organization	Description	Visit
Administration for Community Living	Agency focused on community living, disability, aging, and long-term services and support	acl.gov
Benefits.gov	Benefits screening and information portal	benefits.gov
CDC Developmental Disabilities	Public health information on developmental disabilities	cdc.gov/ncbddd/developmentaldisabilities
Medicaid.gov	Medicaid guidance, including coverage and program information	medicaid.gov
Social Security Administration – SSI	SSI program information for people with limited income/resources who meet eligibility rules	ssa.gov/ssi
U.S. Department of Education – IDEA	Individuals with Disabilities Education Act information	sites.ed.gov/idea

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Education, advocacy and transition resources

Organization	Description	Visit
Job Accommodation Network (JAN)	Workplace accommodation information for employees and employers	askjan.org
PACER Center	Parent advocacy and education resources for children and young adults with disabilities	pacer.org
Understood	Resources for learning and thinking differences	understood.org
Wrightslaw	Special education law and advocacy information	wrightslaw.com

Healthcare, care coordination and family support resources

Organization	Description	Visit
ARCH National Respite Network	Respite care information, advocacy and state resources	archrespite.org
Family Voices	Family-centered advocacy and support for children and youth with special healthcare needs	familyvoices.org
Got Transition	Healthcare transition resources for youth and young adults	gottransition.org
Parent to Parent USA	Parent-to-parent emotional and informational support network	p2pusa.org

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Financial, legal and future planning resources

Organization	Description	Visit
ABLE National Resource Center	ABLE account education and state program information	ablenrc.org
The Arc Center for Future Planning	Future planning education for people with intellectual and developmental disabilities and families	futureplanning.thearc.org
National Disability Institute	Financial wellness and disability economic inclusion resources	nationaldisabilityinstitute.org
Special Needs Alliance	Attorney network and educational information on special needs planning	specialneedsalliance.org

Employer and workplace resources

Organization	Description	Visit
Boston College Center for Work & Family	Workforce, family and employer practice research	bc.edu/content/bc-web/schools/carroll-school/sites/center-for-work-family.html
Business Group on Health	Employer health and benefits strategy resources	businessgrouphealth.org
Harvard Business School Managing the Future of Work	Workforce research and employer strategy resources	hbs.edu/managing-the-future-of-work
SHRM Foundation	Employer resources on inclusive workplaces and employee support	shrm.org/foundation

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