



WHAT IT TRULY MEANS TO PARENT A CHILD OR TEEN WITH CHRONIC PAIN

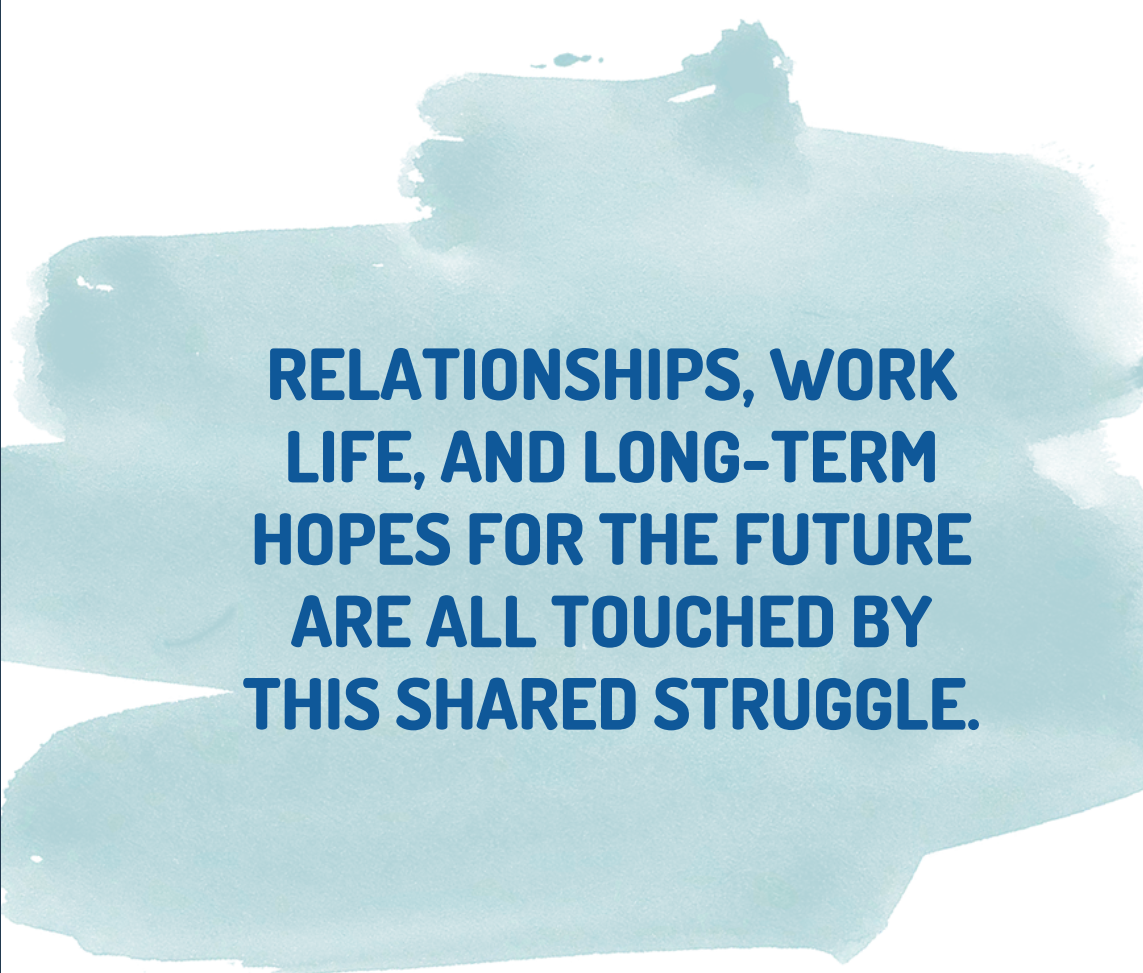


U.S. PAIN FOUNDATION
2025 NATIONAL SURVEY

EXECUTIVE SUMMARY

Pediatric chronic pain is a whole-family crisis that reshapes every aspect of daily life. Millions of children and teens in the United States live with persistent pain that interrupts their education, limits social participation, and demands complex, ongoing medical care. The parents or guardians of these children often shoulder the dual role of caregiver and care coordinator, while simultaneously navigating financial strain, social isolation, and their own health challenges.

In May 2025, the U.S. Pain Foundation conducted a national survey of 2,420 participants, including people living with chronic pain, caregivers, parents of children with pain, and health care professionals. This report draws on the experiences of 87 parents or caregivers who completed the parent-specific survey, offering a focused look at the profound impact pediatric pain has on families. These burdens ripple outward—affecting siblings, extended family, and the stability of the household—creating a reality where the child’s pain becomes the family’s pain. Relationships, work life, and long-term hopes for the future are all touched by this shared struggle, underscoring the urgent need for comprehensive support systems and systemic change.



**RELATIONSHIPS, WORK
LIFE, AND LONG-TERM
HOPES FOR THE FUTURE
ARE ALL TOUCHED BY
THIS SHARED STRUGGLE.**



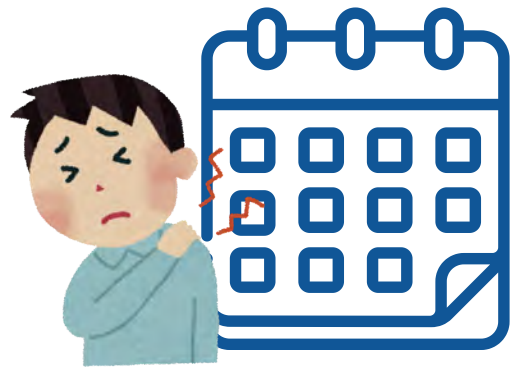
A separate report
delves into findings
from surveying
children and teens
themselves.

DEMOGRAPHICS & PAIN EXPERIENCE

The majority of children represented here are in early to mid-adolescence, with the **largest age group being 13–17 years (59%)**. Girls were overrepresented compared to boys—parents reported that **62% of children identified as female, 33% as male, and 3% outside the gender binary**. While most were **white (93%)**, nearly a third (**30%**) reported an additional racial or ethnic background, highlighting the intersectionality present in this group.

Pain is long-lasting and often complex:

- **92%** had experienced chronic pain for **over a year**
- **1 in 5** had lived with pain for **more than a decade**



Families often manage care across many specialists: **47%** saw **3–6 providers** and **30%** saw **7–20 providers**, with just **14%** seeing **only one provider**. Pain management specialists (**37%**) and pediatricians or primary care physicians (**35%**) were most often in charge of the child's care, followed by neurologists (**16%**) and physical therapists (**13%**).

Appointments are a regular part of life:

- **37%** attended **2–4 per month**
- **23%** had **5+ per month**
- **14%** had **one per month**



DEMOGRAPHICS & PAIN EXPERIENCE

Diagnostic complexity is the norm:

- 35% of families had **more than one child with chronic pain**
- 74% of children had **three or more confirmed diagnoses**
- 14% had **10 or more confirmed diagnoses**



Most-common diagnoses:

- Headache: 41%
- Dysautonomia: 40%
- Postural orthostatic tachycardia syndrome (POTS): 37%
- Back pain: 35%
- Ehlers-Danlos syndrome (EDS): 33%
- Chronic migraine: 32%



Parents also frequently reported children having **nerve or neuropathic pain**, **complex regional pain syndrome (CRPS)**, and **joint hypermobility syndrome** or **hypermobility spectrum disorder**. Additional conditions missing from the survey list but repeatedly written in include **amplified musculoskeletal pain syndrome (AMPS)**, **mast cell activation syndrome (MCAS)**, and **pediatric acute-onset neuropsychiatric syndrome (PANS)**.

Uncertainty remained high—**61%** suspected additional undiagnosed conditions, most often **EDS**, **POTS**, or **myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)**.

PARENTAL IMPACT IS PROFOUND

Parenting a child who has chronic pain is physically, emotionally, and financially draining. The burden is magnified by the fact that **61% of parents reported also living with chronic pain themselves**, creating a **dual caregiving and self-care challenge**. Over half—**54%**—experienced physical complications from neglecting their own medical or physical needs.

Burnout and strain are common:

- 68% of parents felt **overwhelmed or constantly stressed**
- 67% **lacked time** for self-care
- 64% reported **emotional or mental strain**
- 56% struggled to **balance caregiving** with other family responsibilities
- 49% experienced **physical exhaustion**



Workforce participation was heavily affected, with lack of assistance playing a major role. **41%** of parents were unable to work. **31%** lacked flexible work arrangements to accommodate their child's medical needs; **25%** could not take time off work for medical appointments. **24%** had changed careers to provide care, and **18%** had lost jobs due to caregiving demands.

95% received no caregiver benefits from employers.



PARENTAL IMPACT IS PROFOUND

The emotional toll on parents is vast:

- 89% felt anxiety about **their child's future**
- 77% reported **heightened stress**
- 70% felt **helpless**
- 63% experienced **guilt**
- 52% reported **sadness or depression**

48% felt they've lost their identity as individuals.



Isolation compounds these challenges. **66%** of parents felt cut off from friends or family who don't understand, **53%** felt disconnected from other parents not facing similar experiences, and **51%** lacked time to maintain social connections.

Almost 50% of parents said they do not have time for self-care or emotional support.

While **peer connection** offers relief, it's underutilized. Only **46%** of parents had joined a peer support group—yet most nonparticipants said they would join if **privacy, flexibility, and compassion** were prioritized.



CARE IS FRAGMENTED, DELAYED, AND EXPENSIVE

Families described **navigating a tangled web** of specialists, referrals, insurance barriers, and high costs. Care was often inconsistent and disjointed, with **36% reporting that there was no coordinated approach to managing their child's care across specialties**, and **61%** encountering difficulty when trying to coordinate between different providers or specialists.

Out-of-Pocket Spending on Pain Care (excluding health insurance premiums)

- 30% spent \$1,001–\$5,000/year
- 25% spent \$5,001–\$10,000/year
- 18% spent over \$10,000/year
- 17% spent up to \$1,000/year

51% OF FAMILIES HAD DECLINED AT LEAST ONE TREATMENT FOR THEIR CHILD IN THE PAST YEAR DUE TO COST.

Barriers to Care

- 72% faced **long waits** for referrals or new providers
- 52% **lacked local pain specialists**, and 40% had **limited local pediatric specialists**
- 55% **lacked insurance coverage** for certain therapies
- 48% faced **high co-pays or deductibles**
- 39% experienced **insurance delays or denials**
- 39% faced **prior authorization** challenges
- 37% were subject to **step therapy/fail-first** requirements

Telehealth Access and Use

Telehealth has become an important tool for families navigating pediatric chronic pain. The option offers flexibility when in-person visits are difficult due to mobility or mental health challenges, distance, or symptom flare-ups. **Over three-quarters (78%)** of families have used telehealth for pain management, and **77%** of those found it helpful.

For families not currently using telehealth, **53%** believe it would be helpful if available. And **24%** reported that limited availability of telemedicine options have impeded access to care.

IMPACT ON FAMILY SYSTEMS

Raising a child who lives with chronic pain reshapes the entire household. Nearly **9 in 10 families** reported **increased stress** among members, **47%** struggled to maintain relationships with extended family or friends, and **46%** noted more tension or conflict at home.

Romantic relationships also suffered: **45%** of parents reported strain, **38%** experienced loss of intimacy, and **12%** linked caregiving stress to divorce or separation.

Siblings often navigate underrecognized hardships:

- 44% experienced **changed sibling relationships**
- 33% felt **jealous**
- 33% **adjusted behavior** to accommodate the child with pain
- 32% felt **neglected or overlooked**
- 31% had **trouble coping**
- 30% experienced their own **emotional distress**
- 26% took on **caregiving roles or additional chores** at home



**CHRONIC PAIN DOESN'T
JUST AFFECT THE CHILD
—IT RESHAPES THE
ENTIRE HOUSEHOLD.**

EDUCATION SYSTEM STRUGGLES TO ACCOMMODATE

When a child lives with chronic pain, the school experience is often one of **the first casualties**—with disruption extending beyond academics to peer relationships and extracurricular activities.

Attendance disruptions are severe and persistent.

Nearly every family reported some form of missed instructional time, and for many, it is significant:

- 47% of children were **often late** or had to **leave school early** due to pain or medical appointments
- 46% frequently missed **entire school days**
- 44% required **frequent breaks** during the day to manage symptoms
- Among those arriving late or leaving early, missing entire days, or needing frequent breaks, 46% missed **2-4 days per month**
 - 31% missed **7+ days per month**
- Only 7% rarely or never missed school

29% of all respondents were in **full-time homeschooling**, 8% used **hybrid** attendance models, and 8% were classified as **hospital-homebound**.

Academic performance is widely affected. Pain, fatigue, and medication side effects make it difficult for children to keep pace:

- 76% had difficulty **concentrating or staying focused**
- 50% struggled to **complete assignments** on time
- 34% saw a decline in **grades or test scores**
- Only 14% reported no significant academic impact



EDUCATION SYSTEM STRUGGLES TO ACCOMMODATE

Formal accommodations help—but are not guaranteed. Even when families secure them, the process is often complex, emotionally draining, and inconsistent across districts:

- 50% had a **504 Plan**
- 26% had an **IEP (Individualized Education Plan)**
- 21% had **no formal accommodation plan**
- 4% were **denied support altogether**
- 40% of families whose child had or was denied an accommodation plan **relocated or changed schools** to access these supports



EVEN WHEN FAMILIES SECURE ACCOMMODATIONS, THE PROCESS IS OFTEN COMPLEX, EMOTIONALLY DRAINING, AND INCONSISTENT ACROSS DISTRICTS.

Most-common accommodations

- Extended time for assignments and tests (77%)
- Access to a school nurse or medical support (68%)
- Breaks during the school day (67%)
- Reduced physical activity requirements (58%)
- Permission to eat or drink in class (53%)
- Quiet or comfortable environments (52%)



EDUCATION SYSTEM STRUGGLES TO ACCOMMODATE

Social and emotional costs are high.

School is often as challenging socially as it is academically:

- 74% struggled to participate in **school activities or events**
- 67% felt **isolated from peers** due to their condition
- 55% struggled to **maintain school friendships**
- 52% reported stigma or misunderstanding **from classmates**
- 44% experienced stigma or misunderstanding **from teachers or staff**
- 42% faced **bullying or teasing** at school
- 30% said **teachers do not understand** their pain

Gym and extracurricular participation is restricted:

- 36% could not participate in **PE or gym** at all; another 33% participated only in a reduced capacity
- 43% were unable to join **extracurricular activities like sports or clubs**, while 39% had reduced participation

Parents fear long-term educational consequences:

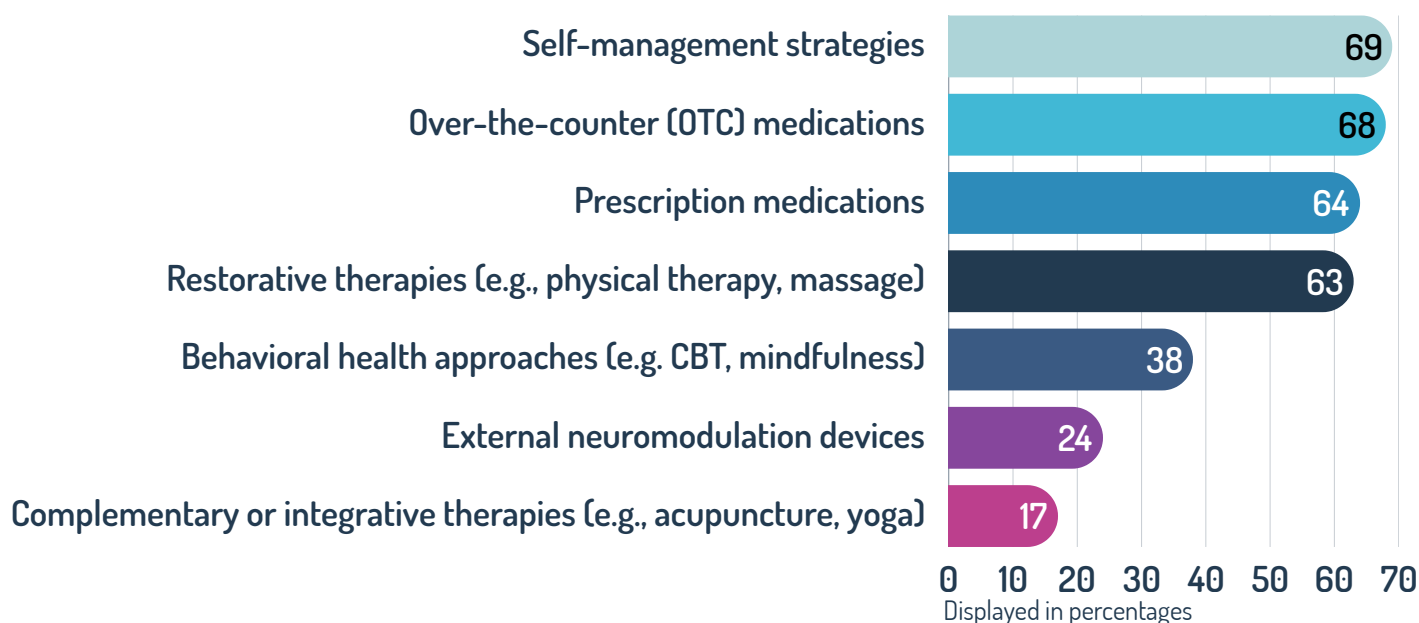
- 71% worried about children **balancing education with ongoing health needs**
- 59% were concerned about **access to higher education**
- 35% anticipated their child **needing ongoing supports** like 504 Plans or IEPs
- 23% feared their child **may not graduate or progress** to the next grade



PAIN MANAGEMENT: STRATEGIES, GOALS, SHORTFALLS

Families managing pediatric chronic pain rarely rely on a single approach. Instead, they pursue a **multimodal strategy** blending **medications, restorative therapies, behavioral health**, and **self-management techniques**. This range of approaches reflects determination and creativity, but it also underscores a sobering reality—**most treatments are only “somewhat effective,”** and few deliver consistent relief.

CURRENT PAIN MANAGEMENT APPROACHES UTILIZED



Even with this diversity of approaches, **effectiveness ratings remained modest**. **Self-management**, the most-utilized approach, was rated as “effective” by only **17%** of families, though **72%** described it as “somewhat effective.” **Restorative therapies** saw similar outcomes—**11%** reported them as effective and **67%** as somewhat effective. **Complementary therapies** performed slightly better in perceived benefit (**33%** effective, **40%** somewhat effective), but they were less widely used.

Medications were commonly utilized—out of families whose children took any kind of medication, **81%** used OTC medications, **42%** used OTC topicals or patches, **34%** took antidepressants for pain relief, and **32%** used prescription anti-inflammatories. But just **14%** rated medications as effective, with **70%** calling them somewhat effective.

PAIN MANAGEMENT: STRATEGIES, GOALS, SHORTFALLS

Emotional Impacts

The majority of families recounted significant emotional impacts of pain for their child: 76% experienced heightened **anxiety or worry**, 72% reported **irritability or mood swings**, 63% struggled to manage **anxiety or stress**, 61% experienced feelings of **sadness or depression**, and 48% **felt hopeless**.

Coping and Self-Management

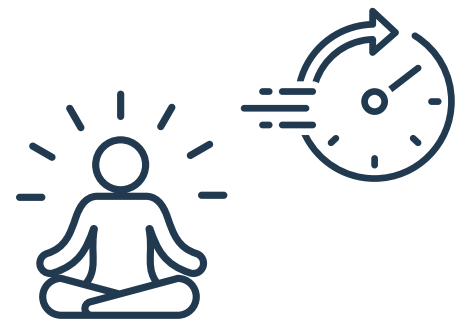
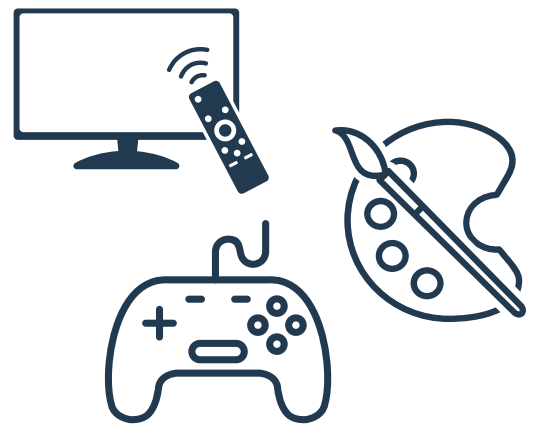
Many children leaned on activities that provide **distraction, comfort, and a sense of normalcy**:

- Watching shows or movies: 63%
- Video games: 43%
- Art projects: 38%
- Spending time with friends: 29%
- Reading, writing, or journaling: 22%

Most incorporated some form of **self-management** to address their pain:

- Distraction: 85%
- Activity modification or pacing: 72%
- Mindfulness or meditation: 45%
- Nutrition or movement: 42%
- Sleep hygiene: 40%

Sleep problems are a major component of the pediatric pain experience. **Three-quarters (75%)** of children had difficulty falling asleep, **62%** had trouble staying asleep, and **30%** slept too much.



PAIN MANAGEMENT: STRATEGIES, GOALS, SHORTFALLS

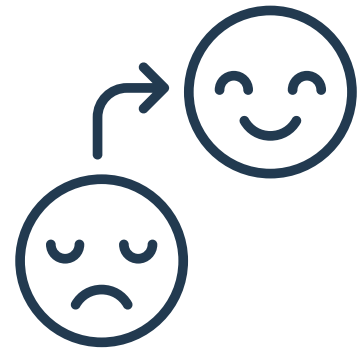
Primary Goals of Pain Management

Understandably, pain relief for their child was a primary goal (**85%**), but families' treatment priorities went further:

- Enhanced quality of life: 89%
- Improved mood or emotional well-being: 82%
- Improved mobility or physical function: 64%

Key Gaps & Needs Identified by Families

- More-effective medications: 58%
- Greater access to complementary therapies: 58%
- Better access to pain specialists: 48%
- More restorative therapy options: 41%
- More mental health support: 37%



These findings make clear that families are working tirelessly to **combine multiple strategies** in the hope of better outcomes, yet they are navigating a system where **the available tools often fall short** of their goals. The emphasis on **quality of life** and **emotional well-being** highlights the need for treatment plans that address the **whole child**—not just their physical symptoms.

RESEARCH PARTICIPATION & ACCESS

Participation in research studies or clinical trials is low—likely driven by a striking lack of awareness of pediatric pain research.

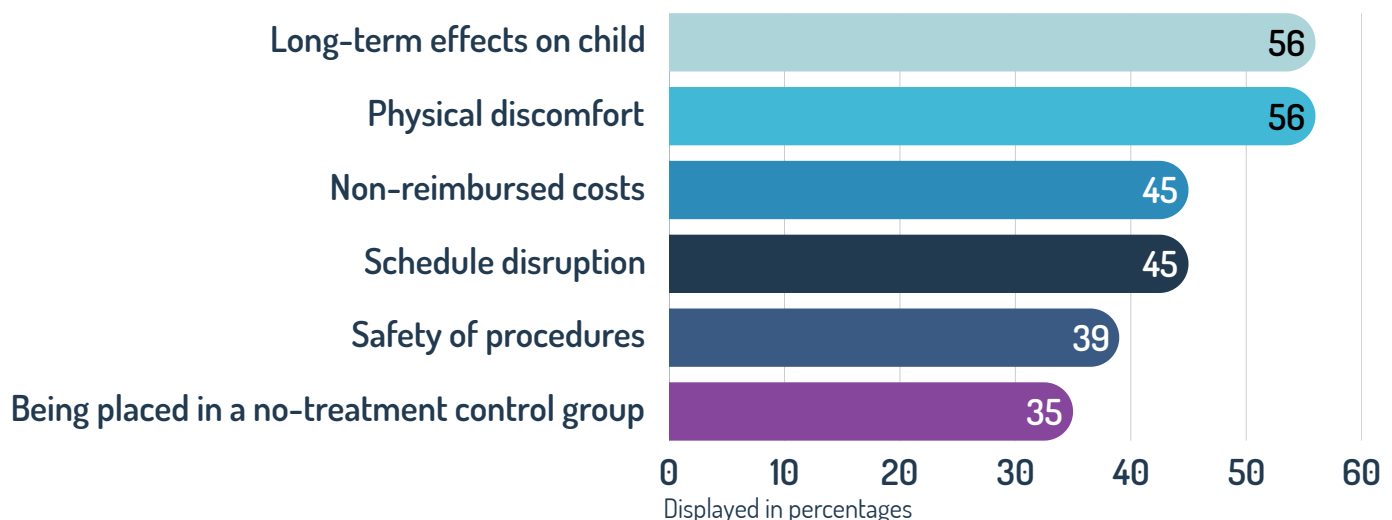
84% of surveyed families had never participated in a research study, while **15%** had participated at least once. Despite low engagement, **53%** said they would be willing to participate in the future, and another **38%** would consider participating—suggesting untapped potential if barriers are addressed.

Awareness Gap

- **68%** of parents felt there is not enough information available about pediatric pain research studies or clinical trials
- **74%** had never been approached by health care providers about participating in a pediatric pain research study
- **17%** had been approached once or twice; **9%** had been approached multiple times

CONCERNS ABOUT PARTICIPATION

Families weighed the risks and disruptions involved in joining research



These concerns reflect both logistical barriers (**cost, scheduling, lost income from time off work**) and procedural factors (**side effects, safety, privacy, treatment access**) that must be addressed to increase participation rates.

RESEARCH PARTICIPATION & ACCESS

Support Needed for Participation

When asked what would **make research participation feasible**, parents identified key supports:

- Travel reimbursement or assistance: 78%
- Clear, transparent communication (process, goals, expectations): 74%
- Flexible scheduling: 72%
- Virtual/remote participation options: 66%
- Financial support for related costs (childcare, lost wages): 54%
- Emotional support for child and family: 48%



Research Priorities

When ranking areas that need more research attention, families prioritized studies that could directly improve both the **medical** and **lived experience** of pediatric pain:

- Long-term impact of pain on **development and quality of life**: 77%
- Education and training on pediatric pain for **providers**: 75%
- **Emotional and psychological impacts** of pain: 69%
- Pain and **co-occurring conditions** (e.g., anxiety, depression): 62%
- **Medication** options: 60%
- **Non-medication** options: 58%

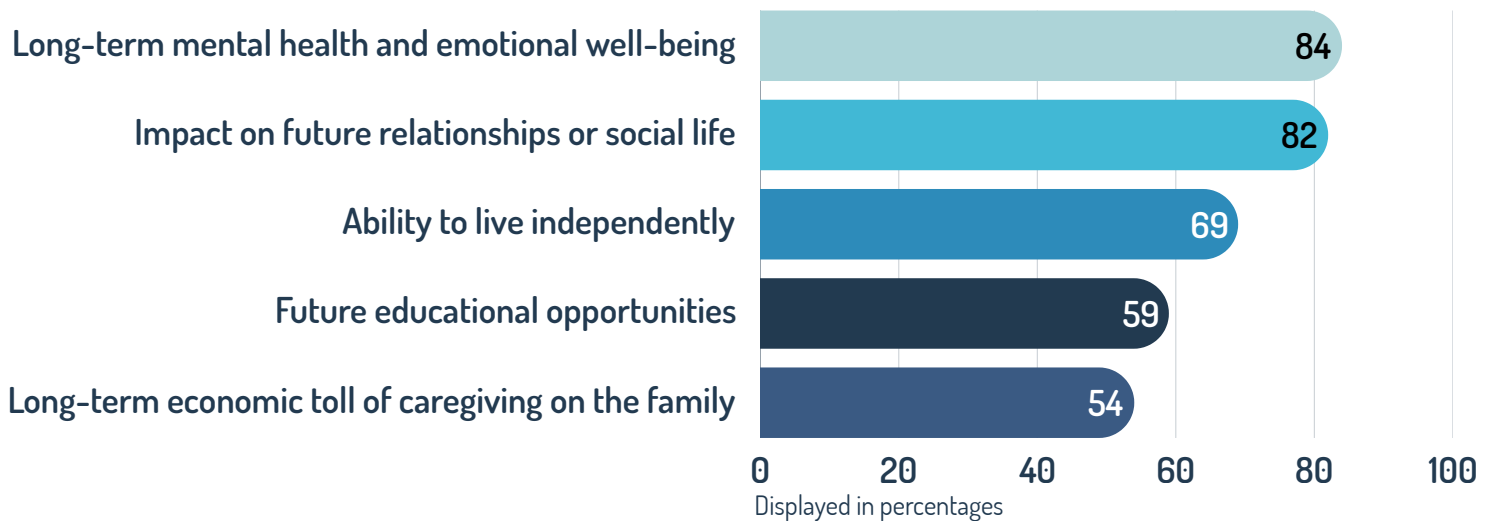


These priorities align closely with families' needs expressed throughout the survey—better-trained providers, more-effective treatments, and care models that address the **whole child**, including emotional health and educational outcomes.

THE FUTURE FEELS UNCERTAIN

Parents' worries extend far beyond managing daily symptoms—they carry deep concerns about their child's **long-term health, independence, and emotional well-being**.

TOP PARENTAL CONCERNS ABOUT THEIR CHILD'S FUTURE



These concerns reflect fears that childhood chronic pain will continue to shape every stage of adulthood—from relationships and education to financial security. Economic worries are especially high, with more than half anticipating **serious financial strain** from lifelong caregiving. Nearly one-third also fear **lasting emotional and relational effects** on siblings, underscoring the **multi-generational impact** of pediatric pain.

RECOMMENDATIONS

Families raising a child with chronic pain need coordinated, comprehensive solutions that address both medical and non-medical needs. Based on the findings, the following priorities emerge.



Treat pediatric pain as a whole-family crisis.

- Integrate parent/guardian mental health services, paid leave, respite care, and peer support into care plans.
- Recognize and address the multi-generational impacts on siblings and extended family.

Improve early diagnosis and specialist access.

- Train providers in pediatric pain conditions; standardize diagnostic tools.
- Expand regional, interdisciplinary pediatric pain clinics, especially in underserved areas.

Remove barriers to care.

- Reform insurance to eliminate delays, broaden approved therapies, reduce co-pays, and end step-therapy/fail-first requirements.
- Offer navigation assistance for families managing complex care; expand telehealth access.

Embed support in schools.

- Train educators and staff to understand pediatric pain and reduce stigma.
- Ensure consistent access to 504 Plans, IEPs, and accommodations such as flexible scheduling and modified workloads.

Equip parents and guardians.


- Provide educational resources, research participation support, and tools or apps to track symptoms, organize medical history, and coordinate care.
- Strengthen workplace protections for parents managing medical care.



CONCLUSION

Pediatric chronic pain is a **national family health crisis**. It erodes mental health, disrupts education, destabilizes finances, and strains relationships. The impact is not limited to the child: Parents, siblings, and extended family members all bear the weight, **often without adequate recognition or support**.

Families are already resourceful—combining therapies, coordinating complex care, and fighting for educational accommodations—but they cannot shoulder this alone. Without systemic change, the cycle of pain, isolation, and lost potential will continue. With **coordinated health care, flexible educational systems, financial safeguards, and family-centered support**, families can ensure that a child's future is shaped by possibility—not limited by pain.



**PEDIATRIC CHRONIC PAIN IS
NOT JUST A CHILD'S
BURDEN. IT'S A FAMILY
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