# **Policy Principles 2024**



These principles constitute National Patient Advocate Foundation's (NPAF) person-centered policy options for healthcare reform that amplify perspectives of patients and caregivers to equitably improve access, affordability and quality.

Each of the twelve topic areas features pragmatic policy approaches addressing physical, mental, behavioral, and financial health needs holistically – all essential for patients' well-being. Updated annually, this document aligns health equity objectives with strategic policy and advocacy engagement opportunities most likely to improve outcomes for patient populations experiencing persisting healthcare disparities, discrimination and distress.

NPAF uses these principles as its operational playbook in determining specific positions and priorities for engagement through community outreach, grassroots mobilization, and legislative, regulatory, and other influential advisory roles and advocacy actions taken throughout the year.

### Advancing Person-Centered Care: Equitable Access, Affordability and Quality

Social drivers of health, persisting inequities and the complexity of the US healthcare system create barriers, burdens and disparities that interfere with physical, psychosocial, and financial health. These hardships are exacerbated for communities of color, LBGTQ+ patients and others coping with complex or chronic conditions, including substance use disorders, who are living on low-income or in healthcare shortage areas.

NPAF prioritizes policy approaches that expressly consider the impact of social drivers, inequities and other factors that influence health and well-being as part of improving care access, affordability and quality. Through our strategic advocacy efforts, we build powerful community connections and collaborative partnerships across multiple sectors to pursue system-focused solutions aligned with the following principles:

# 1. Financial and Social Needs Navigation

- a. Establish expeditious access to quality financial and social needs navigation as a standard of care and a key feature in improving unmet needs relative to physical, mental, behavioral, and financial health outcomes.
- b. Integrate needs navigation services that assess and address individuals' financial and social concerns by linking patients to available financial assistance, household material supports (i.e., food, utilities, housing, transportation) and other safety net resources in all care settings early on and throughout the course of all complex or chronic conditions.
- c. Intensify research investment to develop effective and well-supported evidence evaluating the impact of needs navigation intervention in addressing social drivers of health, mental and behavioral health issues, multi-generational impacts, financial and psychosocial distress, safety net utilization and outcomes disparities.

d. Expand federal navigation services recognition and reimbursement to include social and financial risk assessment integrated with responsive needs navigation services intervention availability in all care settings.

## 2. Medicaid and Children's Health Insurance Program (CHIP) Expansion

- Strengthen the coverage, services, and overall experience of Medicaid and CHIP to meet the multidimensional needs of all limited-resourced families coping with complex or chronic conditions.
- Avoid limitations on Medicaid eligibility, coverage and benefits that impede access to care, including block grant financing, enrollment hurdles, and burdensome cost-sharing or work requirements for beneficiaries.
- c. Increase federal reimbursement rates for mental and behavioral health providers that serve CHIP and Medicaid populations.
- d. Provide resources to address treatment capacity and access to mental and behavioral health services that could support increased collaboration and participation between public and private partnerships.
- e. Provide incentives and opportunities for mental and behavioral health providers that serve in rural or medically remote areas, such as income support, housing assistance and forgiveness for student loans.
- f. Provide tax credits for universities and community colleges that provide mental and behavioral health services for reduced or sliding rates to the community.
- g. Provide improved mental and behavioral health and substance use disorder treatment by eliminating the Institutions for Mental Diseases (IMD) exclusion for residential treatment facilities.

#### 3. Federal Poverty Level and other Safety Net Supports and Services

- a. Federal poverty threshold adjustments and other program eligibility requirements must not interfere with the health and well-being of patients and families who rely on these safety net supports and services.
- b. Increase research investments supporting the development and dissemination of effective interventions that link limited-resourced populations with available financial support and safety net programs.
- c. Enhance support for community-based efforts and encourage collaborations between universities, businesses and other private entities to recruit and retain qualified mental and behavioral health professionals with diverse backgrounds who have demonstrated effectiveness and experience.

- d. Develop treatment options and direct resources to educate communities and leaders about pervasive negative physical, mental and behavioral health outcomes due to systemic racism and to support the needs of populations experiencing the disabling distress that results from systemic racism and discrimination.
- e. Include information about existing mental and behavioral health treatments, including substance use disorders, that supports collaboration and coordination between safety net programs such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC Program), Temporary Assistance for Needy Families (TANF Program) and the Supplemental Nutrition Assistance Program (SNAP).

## 4. Obtaining and Using Health Insurance Coverage

- a. All people must have access to adequate and affordable medical, mental and behavioral health care services through insurance coverage that provides essential health benefits, adequate provider networks, and supports social needs regardless of race, ethnicity, gender, age, geographic location, employment and disability status.
- b. Protect all patients from discriminatory insurance policies and practices that can lead to disparate health outcomes. This may include policies that restrict coverage for pre-existing physical, mental or behavioral conditions, impose burdensome cost-sharing requirements or penalties, and impose lifetime coverage limits.
- c. Integrate equitably accessible mental and behavioral health care, substance use disorder treatment, affordable therapies and social support services as part of a holistic approach to person-centered patient care.
- d. Increase the ability for young people to access their parents' insurance for mental and behavioral health treatment above the age of 26.
- e. Require GAO to analyze the current parity for mental and behavioral health treatment from private, for-profit insurance providers and provide Congress with policy options, if applicable, for reform.
- f. Provide coverage for mental and behavioral health needs of patients across the full range of inpatient, residential treatment and outpatient settings and professional providers, including step down services necessary in providing quality care and improved outcomes.
- g. Support the unique mental and behavioral health needs of children and youth, especially those involved in the child welfare system.
- h. Reinforce health insurance plan accountability for conducting robust quality evaluation and providing understandable and person-centered reporting about insurance options, medical, mental and behavioral health care, including substance use disorder, benefits availability and coverage limitations.

- i. All health insurance plans must play a meaningful role in mitigating inequities that includes transparency in providing understandable and person-centered:
  - 1) Information and resources explaining beneficiary rights and responsibilities for all medical, mental and behavioral health treatment options as well as how to enroll in coverage and utilize benefits. This includes benefit design features, costs of care, and processes such as prior authorization, step therapy, and appeals.
  - 2) *Processes* that are evidence-based and flexible to account for patients' physical, mental and behavioral health, financial and social circumstances and support meaningful patient connections to information, resources and services they need to choose and use their plan coverage and benefits effectively.
  - 3) Communications in multiple formats (written, virtual, by phone) that are culturally sensitive and linguistically appropriate, understandable for various health literacy and reading levels and accessible to accommodate hearing, visual or other functional impairments.
  - 4) Protections that preserve patient-practitioner relationships and shared decision-making.

## 5. Expanding Access to Care Through Telehealth Services

- a. Increase resources and investment, including Congressional action, for boosting telehealth technology's reach and availability to improve treatment capacity and access to effective and well-supported medical, mental and behavioral health services.
- b. Telehealth services via multiple means (phone, audio/video, other platforms) must be reliably and equitably available to all populations. Expanding services requires providing intensive mental and behavioral health and substance use disorder awareness, on-going case work, mitigating infrastructure, technology, language and other barriers that impede access for many rural communities and limited resourced populations and aligning with person-centered quality practice standards that reflect regional and cultural disparities as well as patient and caregiver needs and preferences.
- c. Assess all patients to identify their information technology access aligned with person-centered quality practice standards, and support needs for using telehealth services when they are appropriate and accessible. This includes having processes in place to assist in scheduling a telehealth appointment and equipping patients and caregivers with resources and personalized guidance they need to feel prepared for participating in a virtual visit by phone, audio/video or other platforms.
- d. Increase investment in research and skills development training for person-centered telehealth services delivery, including evaluating the quality, effectiveness and impact of these services relative to improving access to medical, mental and behavioral health treatment options, social drivers of health and other factors causing health disparities.

e. Intensify research investment to develop and test practical approaches for using telehealth to accommodate the physical, mental and behavioral health needs of all communities, alleviate healthcare access barriers while promoting accountability for quality improvement, with emphasis on expanding access to quality medical, mental and behavioral health care services, including for substance use disorders, in health care shortage areas and for limited-resourced populations.

### 6. Integrating Personalized and Value-Based Care

- a. Expand access to personalized care, diagnostics and precision medicine to foster shared decision-making and value-based care that prioritizes patient and family needs while also improving health and quality of life outcomes.
- b. Increase investment in medical, mental and behavioral, and health services research with emphasis on integrating the perspectives of diverse patient populations.
- c. Improve accessibility and affordability in clinical trials for all patient populations regardless of diagnosis, income or location. Clinical trials expansion efforts must:
  - 1) Streamline implementation and enrollment processes
  - Develop and disseminate clear and culturally sensitive information about clinical trials and enrollment opportunities collaboratively in communities to effectively reach diverse patient populations
  - 3) Cover routine health costs and non-medical costs associated with trial participation (e.g., transportation costs)
  - 4) Increase outreach, access to and participation from underrepresented populations
  - 5) Implement and improve expanded access provisions that follow established ethical guidelines enabling therapeutic availability for individuals unable to participate in a clinical trial and who have exhausted other treatment options

#### 7. Total Costs of Care and Transparency

- a. Promote solutions that directly lower patients' out of pocket costs and mitigate potential outcomes that raise the amount that patients are expected to pay, including through deductibles, cost-sharing and premiums.
- b. Increase availability of understandable and transparent cost information, resources and public reporting to support consideration of treatment benefits and tradeoffs in the context of person-centered care planning and shared decision-making throughout the care continuum and across all care settings.
- c. Enhance opportunities for patients and their families to learn about and meaningfully discuss the cost of their physical, mental and behavioral health care, both before and after making a

- treatment decision, in ways that are culturally sensitive and responsive to their needs and circumstances.
- d. Apply pricing transparency principles to all sources of patient cost and promote access to information that helps patients make more informed choices and prepare for the financial obligations associated with their care.
- e. Savings generated through discount programs or price negotiations must benefit low-income patients and limited-resourced populations.

## 8. Surprise Medical Bills

- a. Patients must not be held financially responsible for balance bills due to unexpected out-of-network care.
- b. Patients must be notified about out-of-network providers, facilities or services in a timely manner and have access to publicly available network information that is up-to-date and easily accessible. Disclosure, notice and consent forms cannot substitute for meaningful cost of care conversations.
- c. Accurate information about estimated out-of-pocket costs for health services must be provided to patients as early as possible during the time treatment is being discussed so they are aware of their options, costs and protections.

#### 9. Medical Debt and Credit Protections

- a. Provide sufficient protections and time for all patients and caregivers to either contest or reconcile medical bills and debts with providers or payers.
- b. Apply equitable credit rating and fair reporting practices to minimize distressing medical debt burdens that can follow patients and families for years, even after the debt has been settled.
- c. Integrate consumer protections for medical payment products and their marketing practices, including deceptive practices designed to inappropriately increase costs through the use of medical debt credit cards, to promote transparency and patient understanding about costs and benefits.

#### 10. Skilled Communication, Shared Decisions and Patient Engagement

a. Position patients and families as essential partners for contributing person-centered quality care perspectives and expertise in all outreach and engagement in medical, mental and behavioral health treatment options, value-based assessment, quality measures development and health reform initiatives.

- b. Apply transparent processes that consistently include diverse patient and family perspectives throughout the development, implementation and evaluation of new healthcare benefits design, payment and delivery models.
- c. Value-based health reform initiatives must embed practice standards, quality measures and accountability for patient- and caregiver-reported outcomes that evaluate the availability and effectiveness of skilled communication, shared decision-making, care coordination and essential support services that match treatments with patient-determined priorities.
- d. Promote the development and dissemination of care planning resources and decision support tools that foster patient and caregiver communication about their personal values, priorities and preferences to support shared decision-making and goal-concordant care.

# 11. Palliative Care, Pain Management, Psychosocial Support and Rehabilitation Services Integration

- a. Routinely assess all patients with complex chronic conditions for palliative care, pain management, psychosocial support and/or impairment-driven rehabilitation needs throughout the care continuum with appropriate services integration and referrals processes in place across care settings to maximize their quality of life and minimize distress and functional impairments.
- b. Integrate these supportive services with disease-directed treatment as the standard of care in all settings.
- c. Expand availability and accountability for completing professional skills development training in person-centered communication, care coordination and shared decision-making competencies for interprofessional practitioners in all care settings.
- d. Increase health services and other research investments to improve early and integrated delivery of these supportive services that optimize quality of life and mitigate distress for patients and their families.

## 12. Caregivers Engagement and Support

- a. Explicitly identify caregivers or care partners as part of the unit of care and routinely assess, document and address their particular information and support needs.
- b. Systemize equipping caregivers or care partners with the information, training, benefits and resources they need to support them in their caring roles and responsibilities.
- c. Increase investment in research supporting the development and implementation of effective interventions, insurance and employment benefits design and other assistance for caregivers or care partners.