

## COMMENTARY

# Patient Safety in Transition from Pediatric to Adult-Centered Care

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In 2024 the National Quality Forum (NQF) convened four Stakeholder Advisory Councils, each made up of a subset of stakeholders from NQF member organizations with shared interests to identify and address high-priority topics aligned with NQF's vision that every person experiences high-value care and optimal health outcomes. The four councils each represented important stakeholder groups in healthcare—patients and consumers, healthcare professionals, healthcare provider organizations, and researchers and solutions organizations. These councils were convened to encourage dialogue, address stakeholder concerns, and connect peer organizations to share challenges and best practices. This commentary is the second part of the Consumer Stakeholder Advisory Council's work providing a novel approach with practical guidance on key elements of transition, implementation experience and challenges, and measurement options in the United States and throughout the world. In the summer of 2024 the NQF Consumer Stakeholder Advisory Council hosted a webinar, "Transition from Pediatric to Adult Healthcare: Patient Safety and Health Quality Gaps and Solutions," to explore critical issues such as patient safety gaps and successful transition strategies. The event raised awareness about clinical recommendations, evidence of effectiveness for a structured transition process, successful transition practices, and the role of families and caregivers, and highlighted one individual's lived experience. The combination of expert knowledge and real-life experiences made the webinar a valuable and enriching experience for the attendees.

Some important related topics are beyond the scope of this brief commentary, including the effects of aging out of childhood eligibility under public and private coverage, the differences in family vs. patient-centered care, the limited training and pediatric consultation arrangements for adult providers to care for young adult patients with childhood-onset conditions, and the transition from child to adult mental health services. These topics can significantly affect access to healthcare and the timely transfer to adult care, warranting deeper exploration and solutions.

Pediatric and adult healthcare delivery systems and payers must elevate pediatric-to-adult transition as a vital component of care for adolescents and young adults consistent with clinical guidance recommendations from the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians (ACP),<sup>1</sup> as well as transition recommendations from the Medicaid and CHIP Payment and Access Commission (MACPAC) in their June 2025 report to Congress.<sup>2</sup> Unfortunately, youth with special needs may not receive needed transition support from their healthcare providers. This transition gap requires systemwide attention with active partnership from patients and their families and pediatric and adult clinicians.

## PATIENT SAFETY CONCERNS

Transition to adult care is associated with patient safety risks across chronic conditions, including diabetes, inflammatory bowel disease, congenital heart disease, sickle cell disease, intellectual and developmental conditions, behavioral and emotional conditions, and other complex conditions.<sup>3</sup> Numerous studies have reported deterioration in patient health status, disease complications, distress and worry, reduced medication and treatment adherence, and increased acute care use following transfer from pediatric care.<sup>4–6</sup> In contrast to the recognition of safety harms associated with hospital-to-home care transitions and the widespread adoption of patient safety measures, comparable efforts have not been applied in pediatric-to-adult care transitions, based on a comprehensive review of nationally recognized quality measures.<sup>7,8</sup>

Among the few measures identified, the electronic referral loop by sending and receiving providers is critical given the importance of the exchange and reconciliation of current health information across pediatric and adult systems. Numerous pediatric-to-adult health care transition (HCT) safety measures could be considered, such as evidence of a structured HCT process, quality and safety of transfer of care, and adolescent/young adult/family and clinician experience. With the ever-increasing life expectancy of people who experience childhood-onset chronic conditions, the urgency of addressing this topic is garnering greater attention.

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## CHALLENGES IN ACCESSING RECOMMENDED PEDIATRIC-TO-ADULT TRANSITION SERVICES

Accessing continuous healthcare from adolescence into young adulthood is complicated by systemic, clinical, and individual or family factors, including the following:

- Transition practices widely vary, with many not having a formal review process.
- Mechanisms for transition accountability in electronic health records (EHRs) and quality metrics are very limited.
- Shortages of adult primary care providers, medical specialists, and behavioral health clinicians are a barrier, particularly for those with complex conditions and developmental and behavioral conditions.
- Health insurance changes during transition further complicate continuity of care and often result in greater risk of uninsurance among young adults.<sup>9</sup>
- Young adults often do not want to shift from their long-standing relationships with pediatric clinicians.

These challenges carry significant consequences. Youth and families are often ill-prepared for adult care, the onus for navigating between large integrated healthcare systems is frequently left to them, and more adults with chronic conditions are being served in pediatric systems.

### Clinician Education, Training, and Infrastructure Support

Surveys of adult clinicians in large integrated systems and of adult endocrinologists indicate a willingness to accept new young adult patients with improvements in infrastructure (for example, care coordination, pediatric consultative support).<sup>1</sup>

Got Transition®, a program of the National Alliance to Advance Adolescent Health, serves as the national resource center on HCT and developed a structured process called the Six Core Elements of Health Care Transition™.<sup>10</sup> These core elements, with sample customizable tools, address the preparation, transfer, and integration phases of transition. [Figure 1](#) delineates the Six Core Elements activities and tools.

Three different packages, with tools for each core element, are available. Tailored to the type of practice facilitating HCT, there are sample tools for (1) practices transferring youth to adult care, (2) practices transitioning youth to an adult approach to care without changing clinicians, and (3) practices integrating young adults into adult care. Any model of care can incorporate the structured HCT process, which is not condition specific. Got Transition's website includes a quality improvement implementation guide with examples of the use of this approach in primary, specialty, behavioral, and school health/mental health settings, as well as measurement tools.<sup>11</sup>

There is growing evidence that a structured transition program improves population health, patient experience,

and utilization outcomes.<sup>12,13</sup> In addition, there is evidence supporting the feasibility of implementing structured transition programs.<sup>14</sup> A broad range of organizations have successfully implemented Got Transition's Six Core Elements, demonstrating significant improvements in implementing a recommended transition process, increasing patient preparedness for adult care, and improving patient, family, and clinician experience with care.

### Empowering Adolescents, Young Adults, and Families

Empowering adolescents and young adults to transition from pediatric to adult healthcare involves gradually reducing parental involvement, with corresponding efforts to build adolescent and young adult self-management and health literacy skills and leveraging technology. Transitioning from pediatric to adult care is a complex process requiring time and coordination; however, lack of reimbursement for these efforts can limit provider engagement. Starting early can help mitigate some of the challenges that patients and families face.

Key components to empowering youth in healthcare transition include the following:

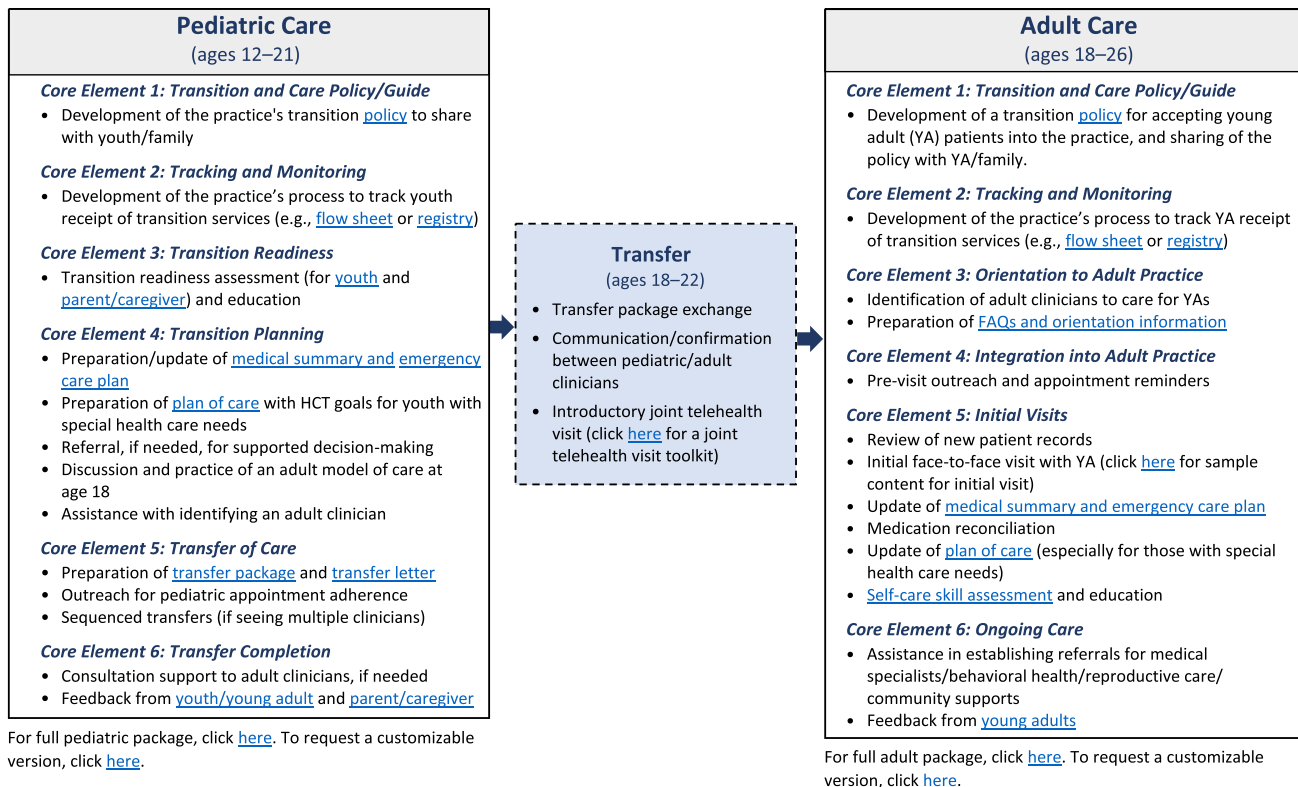
- **Anticipatory guidance and counseling on self-care skill building:** During routine preventive and chronic care visits, clinicians can use tools including transition readiness assessments, such as TRAQ, TRxANSITION, and Got Transition's Readiness Assessments tools, to facilitate conversations about self-management skills.<sup>7</sup> Although these tools may not be directly linked to improved health outcomes, they can help identify needed areas of skills. These conversations can support adolescents and young adults in learning how to manage their medical history, adhere to treatment plans, communicate their health concerns effectively, and advocate for their needs. Transition readiness assessments also help adolescents and young adults gain skills such as scheduling their own appointments, understanding their insurance, knowing their medications and allergies, and maintaining direct communication with clinicians during and between office visits. Adolescents should build individual relationships with clinicians, including through dedicated one-on-one time without a caregiver present, to further build trust and confidence in managing their healthcare.
- **Technology:** Using technology can significantly enhance the healthcare transition experience for adolescents and young adults and support self-management and health education. Patient-facing mobile apps meet adolescents and young adults where they are (online) and offer symptom checkers, appointment scheduling, and educational resources. Expanded access to their health information further empowers youth by enabling them to review their health data and make informed decisions.



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## DELINEATION OF HEALTH CARE TRANSITION ACTIVITIES AND TOOLS



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**Figure 1:** Delineation of Health Care Transition Activities and Tools.

Clinician-facing digital health tools, such as patient portals and EHRs, can streamline communication and send reminders to prompt transition planning conversations, promoting independence and self-sufficiency.

- Strong support network and care coordination: Practices should employ a person-centered, team-based<sup>15</sup> approach to the transition, so adolescents and young adults feel supported and actively participate in decision-making. Ensuring access to care coordination supports those with chronic conditions, helping to facilitate communication between the patient, their family, and both pediatric and adult care teams.
- Parent/caregiver support network: For parents, this transition can evoke a range of emotions<sup>16</sup> as they are encouraged to shift from hands-on support to a more advisory consulting role. It requires relinquishing the decision-making power they have maintained from birth through adolescence and trusting that their young adult will become self-sufficient in advocating for their own care. For many young adults, particularly those with developmental disabilities and those with complex care needs, continued engagement of parents/caregivers is key.

## CONCLUSION

Addressing the challenges of transitioning from pediatric to adult healthcare requires a coordinated, longitudinal effort to prepare, engage, and empower adolescents and young adults. Implementing comprehensive transition approaches consistent with professional recommendations, creating new infrastructure and payment supports, and measuring transition structures and processes will be crucial to address patient safety in transitions from pediatric to adult care.

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