Using Implementation Science to Understand the Pediatric to Adult Healthcare Transition

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KEYWORDS

• Healthcare transition • Pediatric • Adult • Adolescent and young adult
• Intellectual and development disabilities • Childhood-onset chronic condition

KEY POINTS

- The pediatric to adult health care transition (HCT) requires a tailored approach that accounts for the unique needs, abilities, and preferences of adolescents and young adults.
- Using a holistic view of the HCT is necessary to make continued improvements in the field with increasing complexity of clinical care and health care delivery.
- The Consolidate Framework for Implementation Research helps contextualize factors influencing HCT including the individuals involved, their health care system, and their community.

INTRODUCTION

The developmental transition from childhood to adulthood for adolescents and young adults (AYA) is accompanied by a transition from pediatric to adult health care (hereafter HCT) to accommodate the changing health needs as individuals age. The levels and intensity of needed supports vary for an AYA in the midst of the HCT process. Recent work defining knowledge gaps in the HCT field includes identifying how to effectively implement HCT-related interventions given the multilevel factors that impact the HCT process for any AYA.

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Abbreviations	
AYA	adolescents and young adults
CFIR	consolidated framework for implementation research
COCC	childhood-onset chronic conditions
HCT	health care transition
IDD	intellectual and development disabilities
PCP	primary care provider

We will use a case-based approach and an implementation science lens to guide readers in developing a broad understanding of the multilevel factors that impact the HCT process. Implementation science aims to close the gap between what we know to do (evidence-based practice) and what we actually do. Okumura and colleagues highlighted that critical gaps in the HCT field included lack of implementation studies in patients with different levels of medical and social complexities in varying health care settings (eg, pediatric vs adult and university-based vs community).[1,2] Because of the importance of using implementation science in future work evaluating the effectiveness of HCT interventions, we organize this review paper using the updated Consolidated Framework for Implementation Research (CFIR).[3]

Defining the Pediatric to Adult Health Care Transition

The American Academy of Pediatrics, American College of Physicians, and American Association of Family Practice issued guidance in 2002, 2011, and again in 2018 defining the HCT as, *the purposeful, intentional, and planned process of transitioning responsibility and independence in medical care from parents to the young adult patient and from the pediatric to adult medical home*.[4]

Consolidated Framework for Implementation Research

CFIR is one of the most cited implementation science frameworks.[3] CFIR, like other implementation frameworks, aims to predict or explain facilitators and barriers to effective intervention implementation. Said another way, CFIR and other frameworks can be helpful in knowing what contextual factors to address when implementing an intervention to ensure intervention effectiveness.

CFIR includes 5 overarching domains: innovation (the *thing* being implemented); inner setting (where the innovation is implemented); outer setting (setting in which the inner setting sits, may include multiple levels); individuals (those delivering and receiving the innovation); implementation process (activities and strategies used to implement the innovation). We will focus on the individual, inner setting, and outer setting domains and subdomains (**Fig. 1**) as launching points for understanding:

- HCT complexity
- How a local population, community, and context should impact the choice of HCT interventions
- How a chosen HCT intervention and associated implementation strategies may interplay with contextual factors to impact effectiveness

APPLYING CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH TO THE HEALTH CARE TRANSITION

We will work through key CFIR domains using 3 patient cases to highlight issues and complexities that frequently arise for individuals as they transition from pediatric to adult health care (**Box 1**).

Fig. 1. CFIR applied to the pediatric to adult HCT.

Individuals Domain

The CFIR individual domain includes both roles and characteristics of individuals who either receive or deliver an intervention. In HCT, individual roles include the AYA, their caregivers,[5] providers, and other key team members and leaders facilitating the transition. Key individual characteristics encompass needs, capabilities, opportunities, and motivations which shape behavior.

Individuals directly experiencing the health care transition

AYAs enter the HCT process with varying physical, cognitive, and social needs. Most AYAs, regardless of the presence of childhood-onset chronic conditions (COCC), must eventually establish care in an adult-oriented health care setting. Emily's case demonstrates the importance of transition preparation for AYAs without special health care needs. Transitioning to an adult-oriented primary care provider (PCP) allowed for age-appropriate services such as sexual and reproductive health counseling, while her pediatric team and parents supported independence in managing logistics such as appointments and insurance. HCT often coincides with other life transitions, including higher education, launching a career, and independent living.

Box 1
Adolescent and young adult cases and the consolidated framework for implementation research individuals domain

Case 1: Healthy Adolescent with No Underlying Chronic Condition

AYA

- Emily, 18 year old
- No significant past medical history; generally healthy
- Routine visits with pediatrician for well-child checks, immunizations, and minor illnesses
- Lives at home with her 2 parents
- Seeks out informal support from her parents, friends, and mentors for advice
- Expresses anxiety about changing doctors but is eager to take more responsibility for her health
- A bit intimidated by filling out all the paperwork related to her medical and family history

Caregiver

- Family encourages her to learn to manage her own health records, medications, and appointments
- Parent is asked to stay in the waiting room during Emily's first adult primary care appointment
- When Emily turns 18, her parents lose access to her patient portal

Healthcare Provider

- Pediatrician begins discussing the importance of transitioning to an adult PCP as she approaches 18 years of age
- New adult PCP goes through her medical, surgery, family, and social histories to ensure accuracy
- Adult PCP provides resources appropriate for young adults about sexual health, mental health, and lifestyle choices, as well as education about how adult health care differs (such as more direct patient responsibility for scheduling, billing, and preventive care screening)

Case 2: Complex Transition—Childhood Onset Chronic Condition Requiring MultiSpecialty Care and Home Support

AYA

- Jacob, 20 year old
- Cerebral palsy (spastic quadriplegia) diagnosed in infancy, multiple orthopedic surgeries, chronic respiratory issues, depression, and communication difficulties
- Lives at home with father and grandmother
- Followed with pediatric multidisciplinary team including neurology, orthopedics, pulmonology, psychiatry, physical therapy, occupational therapy, and speech therapy
- Uses assistive devices for mobility and communication
- Independent with all activities of daily living (ADLs) but benefits from significant support with instrumental activities of daily living (IADLs).
- Defers to his father regarding to all questions related to health care and shares that he would want his father to make decisions on his behalf if needed

Caregiver

- Parent coordinates home nursing and therapy services
- Started shifting some responsibilities for his care when he was a teenager (eg, watching his father fill his pill box, which he now does independently)
- Worked with Jacob over the past few years to learn more about his treatments, so he now knows the names and doses of all his medications and the reason why he takes them

Healthcare Provider

- Initiated a structured transition plan beginning at age 16
- Support Jacob and his family in gradually increasing his involvement in health care decisions, tailored to his communication abilities

Case 3: Transition Challenges—Patient with Intellectual Disability

AYA

- Sarah, 19 years old
- History of moderate intellectual disability and epilepsy
- Followed with pediatrician and pediatric neurologist
- Lives at home with her parents

- Defers to family members regarding discussion of guardianship

Caregiver

- Parents are primary caregivers, managing appointments, medications, and daily needs
- Parents help to provide supported independence by encouraging her to participate in modified household tasks and self-care
- Sarah's older sister has taken on the responsibility of driving Sarah to medical appointments
- Sarah goes with her sister to the pharmacy to pick up her medications and together, they fill her pill box
- Sarah's sister may pursue guardianship but they are unsure if this is the best next step

Healthcare Provider

- Pediatric team works closely over time with Sarah's parents to teach supported self-care skills and improve communication strategies

COCCs such as sickle cell disease, cystic fibrosis, cerebral palsy, and other forms of medical complexity add additional challenges to the HCT. Both Jacob's and Sarah's cases illustrate some of the unique challenges associated with transitioning an AYA who requires complex, multispecialty care. For example, these AYAs must establish both adult primary and specialty care, as well as navigate increasing responsibility for self-management of their COCC.[6,7] The combination of usual HCT plus added complexity of a COCC make HCT particularly vulnerable and highlights the need for comprehensive support throughout the transition period. This vulnerability can result in serious consequences. For example, organ transplant recipients have higher rates of graft failure during the HCT, and AYAs with sickle cell disease have increased rates of mortality during the HCT.[8]

An AYA's cognitive abilities, including diagnoses of intellectual and developmental disability (IDD), add increased complexity to the HCT and require a tailored approach.[9] Complete independence from a caregiver is not always the end goal, yet transitioning to an adult-oriented care model remains essential to ensure that these AYAs receive age-appropriate care as adults. In the case of Sarah, her moderate intellectual disability necessitates ongoing caregiver support to manage her care needs as a young adult.

For any AYA, with or without IDD, assessing and tracking transition readiness with validated measures such as the Transition Readiness Assessment Questionnaire can guide preparation and the timing of transfer to adult care.[10] For those with IDD, engaging caregivers in the transition readiness assessment process and throughout transition planning is recommended.[11,12]

Caregiving environment

Caregivers have dual roles as individuals: they indirectly experience HCT and help deliver interventions to improve the HCT process. As highlighted by Feinstein and colleagues, caregivers and the caregiving environment are critical for transition preparation.[5] Caregivers' roles include ensuring skill scaffolding, modeling adaptive health behaviors, and gradually decreasing engagement in ways that foster AYA independence. AYAs with IDDs may need ongoing caregiver support as adults ranging from assisting with self-management tasks such as ordering medications to providing decision-making support in the form of guardianship (See *Outer setting*).

For AYAs with COCCs who are planning to live independently, it is important for caregivers to begin to shift disease-management responsibility to their AYA beginning in adolescence. In the adult-oriented health system, the patient becomes the center of their care as the caregiver shifts to a supporting role. Tasks typically performed by a

caregiver during childhood such as preparing medications should be gradually shifted to the AYA.

Health care providers

Pediatric and adult health care providers alike should use a structured framework—such as that outlined in The Six Core Elements of Health Care Transition 3.0—to ensure that AYAs are cared for in a comprehensive and equitable way.[13] As part of the self-care skills assessment recommended by GotTransition in the HCT process, adult providers can use the American College of Physician's condition-specific tools that provide assessments and guidance for providers and patients.[14]

Health care visits should incorporate skill-building by early adolescence.[15] Activities may include providing independent time for AYAs with health care providers without a caregiver present, assessing self-care skills, and specific goal setting for successful transfer preparation.[16] Medical summaries are useful tools to share with adult health care teams and help plan for needed transfers of care.[17] Establishing presence of executive dysfunction, intellectual disability, or learning disability diagnoses through neuropsychological testing helps ensure qualification for resources moving forward. These interventions help to ensure the logistical aspects of transition are managed and gaps in care are reduced.

Other team members, leaders, and champions

Many individuals critical to the success of the HCT process are not directly involved with patients and caregivers. CFIR emphasizes the layered nature of individual roles and their characteristics when implementing interventions into complex health systems. Champions of HCT are necessary, but not sufficient, for successfully sustained HCT program.[18,19] Anchoring on the presence of an HCT champion has led to dissolution of HCT programs. Health system opinion leaders and leaders with authority to make decisions are also critical to any systematic, holistic, and sustainable HCT process.

Inner Setting Domain

The inner setting includes the institutional structural and cultural characteristics—for *both* pediatric and adult settings-related to health care delivery during HCT (**Box 2**). Key persistent characteristics of inner settings include structural characteristics, communication, relational connectedness, and culture. There are aspects of the inner setting that are relevant to implementation or delivery of specific interventions that we exclude only due to scope.

Culture

The culture of a health care organization includes shared values, beliefs, and norms around (1) caring, supporting, and addressing the needs and welfare of patients, health care team members, and other institutional employees and (2) psychological safety, continual improvement, and data informed practice.

For the HCT process, a first delineation is between pediatric and adult health care organizational cultures. Colloquially, patients and providers alike reference *sides* when comparing pediatric and adult health care. Pediatric care settings tend to directly support family involvement in care, which can complicate progressive autonomy and independent decision-making by defaulting to the parent or caregiver. Contrastingly, adult health care settings promote and emphasize individual autonomy, potentially limiting caregiver engagement and causing friction. Both approaches to care, while valid, often lead to an artificial binary about *who* makes decisions, rather than decision-making and caregiver engagement existing on a continuum.

Box 2
Adolescent and young adult cases and the consolidated framework for implementation research inner setting domain

Case 1: Emily

Structural

- Her pediatrician schedules a joint visit with Emily and the adult PCP to introduce them and review as this is supported by their health care system
- Emily subsequently attends visits with the adult PCP independently, building confidence in navigating the health care system

Case 2: Jacob

Cultural

- Overall HCT plan for Jacob involves identifying adult providers familiar with cerebral palsy and its complex care needs, including adult neurologists, physiatrists, pulmonologists, and rehabilitation specialists
- Plan for new PCP to take over care of his depression, eliminating the need to transition to an adult psychiatrist at this time and decreasing the number of upcoming subspecialty appointments

Structural

- Jacob establishes with adult PCP before his final appointment with his pediatrician
- Pediatrician sends a transition summary to his adult PCP outlining his medical history and current treatment plan
- New adult PCP walks through this transition summary with Jacob and his family
- Collaborate on a stepwise approach to subspecialty transition, based on both the pediatric subspecialists' transition policies and also family's preferences
- Adult PCP sends a copy of this plan back to his pediatrician with an open invitation to discuss further questions or concerns over the phone in the coming weeks
- Jacob and his family have their final pediatrician appointment and afterward are considered transitioned
- Home care and therapy services are maintained, with an emphasis on promoting Jacob's independence within his functional abilities

Communication and Relational Connectedness

- The transition coordinator embedded in the pediatric care model ensures all specialists collaborate to provide a coordinated transfer of care
- Social workers assist the family with accessing community resources and vocational support, aligning with Jacob's goals for education and employment
- The adult care team works closely with Jacob's family to ensure continuity of care, prevent fragmentation, and address both medical and psychosocial needs comprehensively

Case 3: Sarah

Cultural

- An adult PCP and care team with expertise in intellectual disabilities and neurology is identified

Structural

- A comprehensive transition plan is developed and integrated into the electronic health record, addressing medical needs, behavioral health, social supports, and community integration
- The adult providers emphasize patient-centered communication adapted to Sarah's cognitive level including prolonging her appointment time
- Sarah establishes with a new adult PCP and her older sister joins her in the examination room
- Adult PCP walks through all aspects of Sarah's history, with her sister answering most of the questions
- Adult PCP and Sarah's sister set up the Medical ID on her phone to have the most significant aspects of her medical history in case she were to have a medical emergency when her family is not present
- Sarah's PCP asks her sister to leave the room and gives Sarah an opportunity to ask questions, share her own concerns, and discuss topics such as substance use and sexual health

- Adult PCP learns that Sarah is sexually active with male and female partners but has not received information about sexual health in the past; they offer information regarding healthy relationships, infection prevention, and pregnancy prevention as Sarah states she does not want to become pregnant
- Sarah shares that she would prefer to discuss this with her sister, so her sister is invited back into the room to discuss further and agree on a plan moving forward
- Adult PCP schedules an appointment in several weeks to follow up on a discussion about guardianship and decision-making, with a plan for Sarah's sister and parents to join her at that upcoming appointment
- The family receives education on navigating the adult health care system

Communication and Relational Connectedness

- Sarah attends visits with a familiar care coordinator who advocates for her needs and assists with scheduling and transportation

There is evidence that pediatric and adult providers alike experience discomfort when caring for AYAs with COCC.[20–22] Multifaceted reasons for this discomfort frequently anchor on differences in usual care in the pediatric versus adult medical home settings. For children with COCCs, the subspecialist often serves as a medical home. For adults with or without COCCs, the PCP services as the medical home and subspecialists as consultants. Many AYAs with a COCC develop comorbidities as they age, increasing their medical complexity in ways not typically seen in children. Conversely, adult providers are expected to manage a broader scope of common chronic conditions such as hypertension. Depending on the prevalence of specific conditions, an AYA with a COCC may be the first person that an adult provider has encountered with that condition.

Structural characteristics

Broken down by subconstructs, structural characteristics include the infrastructure component of a system that exist and are in action on any given day.

Physical infrastructure. The configuration and physical tools or materials in the health care setting constitute physical infrastructure. Differences in tools or equipment between pediatric and adult care can impede HCT. A young adult with cerebral palsy who weighs 30 kg may be too small for the standard equipment in an adult operating room. Differences in standardized materials between pediatric and adult care such as MIC-KEY buttons versus PEG tubes for enteral feeding can result in a facility lacking the correct materials (eg, feeding set extensions) or staff experience to provide necessary care.

Information technology. Information technology includes tele-communication, electronic documentation, and data-related issues. Tools and supports for information technology that work both within and across systems enable the HCT process. For example, the ability to develop an HCT care plan that can summarize an 18+ year medical history and (1) be accessible to patients and families and (2) travel within and between health care systems facilitates the transfer between systems. Data access and tracking is critical for pediatric and adult health care systems alike. For example, registries may help track HCT aged patients and ensure an AYA is not lost to care. A pediatric institution may track individuals aged 12 and over to understand the populations of patients who are experiencing the HCT process and potentially identify gaps when identifying adult-aged patients remaining in the system.[23–26]

Work infrastructure. Work infrastructure includes multiple facets of organizational tasks and responsibilities within and between individuals and teams, general staffing

levels, and resources supporting functional performance of the institution. Our cases include examples of how workflows within and between health care teams are important to implementing HCT-related interventions. The joint visit described in Sarah's case is an example of a warm handoff, which requires work infrastructure that allows coordinated scheduling and business agreements to ensure appropriate billing and revenue generation. A patient's ability to revisit a pediatric provider after the initial adult provider visit in ways that do not complicate care delivery as described for Jacob requires closed-loop communication between care teams.

Scheduling practices in a clinic setting may need to adjust for individuals with behavioral challenges, something with higher prevalence for individuals with IDD like Sarah. Strategies to accommodate patients with sensory processing differences or challenges with behavioral regulation, such as booking as first appointments of the day or limiting wait times, may not be typical practices in adult care settings. While the adult health care system tends to lean toward more episodic care in the setting of crisis or medical concerns, building rapport through more frequent visits focused on health care maintenance (ie, well checks) helps establish relationships with patients and their families. In a system with significant time constraints, frequent visits can also allow for discussion of topics often neglected during the HCT, such as sexual health.[27]

Almost every health care system will care for individuals with overlapping pediatric and adult acute care needs; individuals with cerebral palsy like Jacob benefit from advancements in pediatric orthopedic techniques to manage severe scoliosis and hip subluxation. Despite Jacob being 20 years old, he may benefit from a surgical procedure only offered in a pediatric hospital setting.

We have found that each health care setting has different capabilities and these capabilities should impact which patients receive care.[18,28–30] Examples of this could include a pediatric hospital caring for a patient like Jacob due to a specialized orthopedic surgical procedure or an adult hospital taking care of Sarah for community-acquired pneumonia. Both hospital settings and their staff may struggle to provide evidence-based and developmentally appropriate care. Patients and their families in both scenarios may also feel the impact of having a health care team that either does not feel comfortable or equipped to manage their care needs. Each health care institution determines the scope of practice of employees in different roles. This then informs required training and credentialing practices.

There are also potential patient safety issues that may arise due to organizational workflows and processes. For example, in pediatric care settings, weight-based dosing could result in an overdose in larger patients.[31–33] Conversely, lack of weight-based dosing could overdose smaller adults. In the event of clinical deterioration, availability of appropriately sized equipment often becomes a challenge. While most notable for smaller adults like Jacob who may need pediatric-sized equipment despite transitioning to an adult health care setting, equipment sizing may still be a challenge in pediatric care settings as well.

Communication and relational connectedness

While communication and relational connectedness are 2 distinct subconstructs, we believe there is overlap in the HCT inner setting characteristics that promote them. Communication is the high quality formal and informal information sharing practices within and across the inner setting, whereas relational connectedness is the high quality formal and informal relationships, networks, and teams within and across the health care system. The amount and quality of care coordination and ancillary services in both pediatric and adult health care institutions either enable or hinder information

sharing, and if relationships form and sustain, within and between health care teams, AYA, and their caregiving supports.

It may surprise some to learn that providers and their care teams function as gatekeepers for many healthcare-related services necessary to promote the health and well-being of individuals with COCCs. As discussed in the next section, outer setting, access to and maintenance of support services like home care, day programs, and so on almost always require a provider sign off. This gatekeeping increases in complexity during the HCT process as care is transitioning between providers, teams, and systems. There may also be new needs that develop during the HCT process. There must be both sharing of information (communication) and maintained relationships (relational connectedness) to access and maintain needed supports during the HCT process.

Jacob's case shows more of the care coordination the HCT process may require. First, his pediatric health care setting includes access to both a transition coordinator and social worker who help (1) identify his educational and career goals and (2) connect him with resources. HCT and integration into the adult health care system extend beyond just Jacob's primary care. More nuanced aspects of his medical care coordination include identifying adult medical subspecialists should be transitioned, prioritizing the timing of subspecialists transitioning, and then connecting patients and their families with adult providers. Adult PCPs may be able to take over the care of medical conditions typically managed by pediatric subspecialists, particularly when these conditions are stable.

Jacob also has other ancillary services like physical therapy, occupational therapy, and plans for vocational support. Support services, like nutritionist support, are often more challenging to access for adults than children. Nutritional support, even when available in adult clinical settings, is for common diagnoses like diabetes or heart failure. Other *wrap-around services* seen more in pediatric health care settings like behavioral support teams and child life (eg, Hospital Elder Life Program as an example in the adult health care setting) are variably present.[34]

Additionally, the HCT process includes planning for acute care and procedural needs. (*Which hospital would you go to if needing to be seen in an Emergency Room*? and *What accommodations have been beneficial in the past for procedures or admissions*, *and are these supports available in adult healthcare system*?).[28] Facilitating discussion around acute care needs during the HCT necessitates moving beyond understanding an individual's needs. Pediatric and adult health care teams must understand the capabilities of their partnering health care teams and systems.[30]

Outer Setting Domain

If the inner setting context is a health system-affiliated adult patient-centered medical home, then the outer setting includes the characteristics and networking of entities like the larger health care system, local municipality, state, and country. While outer settings can and do change, these changes often require larger advocacy or lobbying efforts. Understanding the interplay between the immediate health care environment for an AYA and the broader outer setting is necessary to optimize the HCT process (**Box 3**).

Local partnerships, connections, attitudes, and conditions

The CFIR outer setting includes multiple subconstructs relevant to the sociocultural values and beliefs (attitudes); economic, environmental, political, and technological conditions; and networking of entities external to the health care system such as community-based organizations. While relevant to the HCT process, each

Box 3
Adolescent and young adult cases and the consolidated framework for implementation research outer setting domain

Case 1: Emily

Local conditions

- Emily lives in a suburban neighborhood with plans to attend college several states away
- Both her current and future communities have PCPs and specialists that are within her current insurance network

Financing

- Emily is expected to transition to her college health insurance plan when she matriculates, which is a different carrier than her family's insurance
- The college health care center will be in-network for her, as will several specialists

Case 2: Jacob

Local conditions

- Jacob lives in an urban community
- He lives within the same zip code as a large, free-standing children's hospital and an adult hospital that accepts his insurance
- All of Jacob's specialists are within the same health care system, and he has received specialized care from them since infancy

Policies and laws

- Jacob may continue to receive inpatient care at the local children's hospital only until the age of 25
- After the age of 25, he will need special approval for admission to the children's hospital and, outside of a planned procedure that cannot be performed in the local adult hospital, may not receive this approval
- The age at which his specialists will transition him depends on the specialty and his specific provider, as the hospital does not have stated policies for outpatient care

Financing

- Jacob's local children's hospital accepts his insurance and also provides discounted care for those unable to afford specialized services
- Because all of Jacob's care can be accessed in the nearby community, his family does not need to pay to travel elsewhere to receive care

Communication and Relational Connectedness

- The transition coordinator embedded in the pediatric care model ensures all specialists collaborate to provide a coordinated transfer of care
- Social workers assist the family with accessing community resources and vocational support, aligning with Jacob's goals for education and employment
- The adult care team works closely with Jacob's family to ensure continuity of care, prevent fragmentation, and address both medical and psychosocial needs comprehensively

Case 3: Sarah

Local conditions

- Sarah lives in a rural community, which has an adult PCP but minimal specialty care
- The local adult PCP is comfortable providing well-adult care but is not aware of any neurologists in the area who could take over her epilepsy care and is uncomfortable navigating guardianship discussions due to lack of experience with this
- The closest neurologist is over an hour away, and Sarah's family does not have reliable transportation
- Local dentists and gynecologists do not provide sedation for dental and gynecologic examinations, respectfully, so Sarah falls behind on well adult care because of difficulty tolerating these procedures

Policies and laws

- Sarah's family was unable to apply for guardianship before her 18th birthday, so there is a period of time when her parents have to consent for her medical care rather than her sister due to her parents being legal next-of-kin. At times, this made accessing care more difficult due to her parents' progressive medical concerns and inability to physically be present with Sarah for health care appointments

Financing
- Sarah attends visits with a familiar care coordinator who advocates for her needs and assists with scheduling and transportation, but her family struggles to access necessary health care due to the distance to specialists
- Sarah's care coordinator assists her with applying for supplemental security income
- Unfortunately, her zip code is outside of the range for home nursing companies, so she does not receive any home health support outside of her parents
- Her family applies for a waiver, but the waitlist is several years long

subconstruct has nuance that is specific to each locality. For example, social determinants of health are particularly relevant in understanding local community conditions and attitudes. How a local community identifies and addresses disparities during the HCT process due to factors like race, ethnicity, socioeconomic status, disability, and geographic location will impact the quality of health care delivery for AYA and their caregivers.[35]

Policies and laws

In health care delivery, the breadth of policy and law is already large including aspects of clinical care like clinical guidelines, standards for scope of practice, and hospital accreditation standards. For example, some pediatric hospitals set upper age limits for patients who can receive care whereas others do not. This type of system constraint directly impacts the timing of the HCT process. Some professional groups' organizations have developed guidelines and centers of excellence accreditation standards (eg, Cystic Fibrosis Foundation) that designate 21 years of age as the age at which most individuals should complete the HCT process.[36]

For individuals like Sarah who may not have capacity to make all decisions, the impact of laws goes further to include legal guardianship or other forms of supported decision-making (**Fig. 2**). Decision-making support for all adults exists along a spectrum, ranging from informal assistance provided by family and friends, to supported decision-making and health care powers of attorney to formal legal arrangements such as guardianship. Guardianship is a legal process where a guardian is appointed to make decisions on behalf of an adult who is unable to do so on their own. The most appropriate arrangement for any individual depends on various factors and may evolve over time. However, it is significantly easier to progress

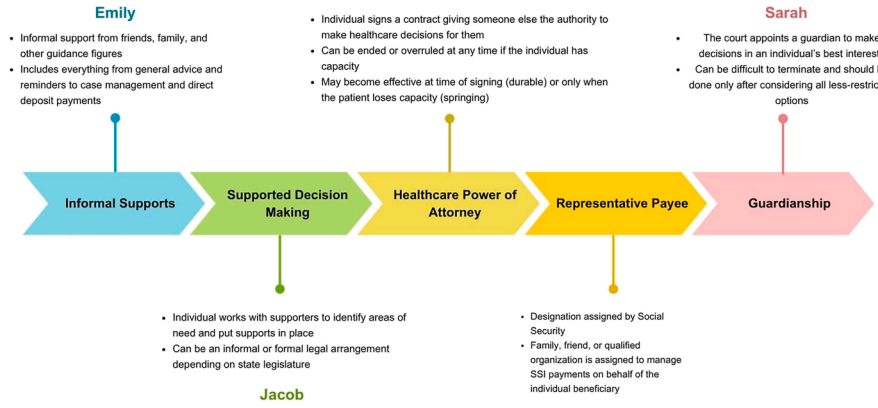

Fig. 2. Spectrum of decision making supports.

from less restrictive to more restrictive options than to reverse formal arrangements like legal guardianship.

Regardless of arrangement, each AYA's autonomy is central. Even when guardianship represents the safest and most appropriate option, individuals should be supported in making their own choices. Support arrangements should maintain flexibility, acknowledging that decision-making abilities vary across contexts and time. This flexibility in support is more easily achieved in informal arrangements, but equally important in formal ones. Sarah and her family met with a social worker and legal advisor to discuss the complexities of applying for guardianship for Sarah. Due to her intellectual disability, they decided that guardianship would best support Sarah. Because her parents are aging and no longer able to drive, they decided that Sarah's sister would become her legal guardian to continue to help Sarah make medical decisions and manage her finances in adulthood. Ultimately, respect for the individual and the goal of balancing empowerment and autonomy with safety should guide not only the selection of the most suitable support option, but every subsequent decision made within that framework.

Financing

Financing includes funding from external entities that is available to fund HCT process-related efforts, primarily as reimbursement. Since 2023, providers can bill for transitional care services using *pediatric-to-adult transition counseling: Z71.87*.[37] Whether a health system uses a pay-for-performance or value-based care model for reimbursement also impacts how health care models are designed and implemented. The nuance of how Medicaid expansion through the Affordable Care Act impacted care quality and access to services for AYA through the HCT process is out of scope.[38] However, it is important to understand that value-based payment programs and HCBS 1915c waivers both have evidence of facilitating access to care coordination and ancillary supports during the HCT.[39,40] Over of a third of children in the United States have Medicaid as primary insurance versus less than a quarter of adults.[41] Many AYA change their insurance during the HCT process (eg, fall off parental insurance at age 26 years, and so on). A national study showed that health insurance uninsured status in 2022 increased from 5.2% for older adolescents aged 15 to 18 years to 13.3% in young adults aged 19 to 25 years.[42] Insurance status affects every level of the HCT process from challenges finding adult providers who take Medicaid to differences in embedded services in medical homes to processes for care approval.

Understanding access to alternative sources of funding or innovative payment models must underscore efforts to improve the HCT process. Community-based organizations often have grant opportunities aimed toward at-risk populations. At the state level, Title V programs (eg, maternal and child health block grants) and Medicaid redesign efforts have allowed growth and development of HCT programs and comprehensive care models.[43,44]

Professional organizations and foundations alike look to fund efforts aimed at improving care for diverse and increasingly complex populations across the life course. Examples include the American Academy of Development Medicine and Dentistry funds medical schools to improve education around the care of individuals with IDD[45]; The National Institute of Child Health and Human Development included HCT as a strategic area; the Mother Cabrini Foundation supported increasing workforce development and access to care for individuals with IDD and other COCCs. The sustainability challenge after initial funding remains, though, as a critical gap in HCT efforts.[18,19]

SUMMARY AND APPLYING HEALTH CARE TRANSITION BEST PRACTICES

The pediatric to adult HCT affects all AYA, with or without a COCC, as they navigate moving from pediatric to adult health care. CFIR emphasizes multilevel factors that impact the HCT process:

- Individuals: AYA, their caregivers, their health care providers, and other HCT-related leaders
- Inner setting: characteristics of the pediatric and adult health care settings
- Outer setting: External characteristics and networking of entities like the larger health care system, local municipality, state, and country

Recognizing the interplay of these CFIR domains within local contexts enables health care providers and their teams to choose and implement effective HCT interventions for their patients and communities.

CLINICS CARE POINTS

- Each adolescents and young adults (AYA)'s autonomy should always be maximized and prioritized throughout the health care transition (HCT) process. Individuals should be supported in making their own choices with their personal goals, values, and preferences remaining central to all decisions affecting their lives.
- Health care system structural and cultural characteristics—for *both* pediatric and adult settings—related to health care delivery impact care quality both during and after the HCT process.
- Using a holistic approach to identifying gaps in the HCT process can enable identifying sustainable solutions.

DISCLOSURE

The authors have nothing to disclose.

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