

## Development of a multi-level/multi-modal intervention for health care transition preparation

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### ABSTRACT

**Aims:** Health care transition (HCT) to adult care and young adult disease self-management is a multi-step process involving three major stakeholders – the adolescent, the caregiver, and the provider. Preparation gaps exist within each of these stakeholder groups. This paper presents the development of the Intervention to Promote Autonomy and Competence in Transition-aged Youth (IPACT), a multi-level (adolescent, caregiver, provider), multi-modal (interactive skill building sessions, educational materials, videos) intervention to address gaps in all three stakeholder groups simultaneously and help support achieving the three core elements of HCT planning. **Methods:** Eight processes were utilized to develop the IPACT intervention, including reliance on existing literature and materials, stakeholder feedback at multiple points during development, and regular support and guidance from service liaisons within each of four tertiary-care clinics targeted for this intervention within a large, urban children's hospital.

**Conclusions:** IPACT includes the conceptual schema, logic model, intervention curriculum components, and implementation timeline. IPACT could be used by programs to simultaneously address gaps in stakeholder HCT planning knowledge and skills.

### 1. Introduction: the case for a multi-level, multi-modal intervention

Over the past three decades, therapies for pediatric onset illnesses have improved to the extent that 90 % of children with child-onset illness will survive into adulthood.<sup>1</sup> There were an estimated 7.3 million 12–17 year-olds in the U.S. as of 2020 with a special health care need.<sup>2</sup> Assuming that individuals in this group are evenly distributed by age, approximately one million 18 year-olds with special health care needs could transition into the adult care system annually.<sup>2</sup> The transition process appears to be successful for most adolescents and young adults with special health care needs (AYASHCN) if their conditions are mild.<sup>3</sup> As the complexity of the condition increases, so does the resultant morbidity and mortality if transition planning is not successful.<sup>4,5</sup>

The Maternal and Child Health Bureau (MCHB) has defined successful transition planning (the MCHB core transition outcome)<sup>2,6</sup> as consisting of three core elements: 1) the adolescent patient meeting with the provider alone; 2) the provider actively working with this youth to make positive choices about their health, gain skills to manage their health and health care, or understand the changes in health care that happen at age 18; and 3) the provider discussing the eventual shift to an adult care provider.<sup>7</sup> Although the core elements primarily set expectations for patients and providers, caregivers play a fundamental role through their acceptance of or resistance to their adolescent meeting with the provider alone. Thus, AYASHCN, their caregivers, and their pediatric health care providers must all have the requisite knowledge and skills to help prepare for successful transition to adult-based care. It should be noted that MCHB does not address all issues of the broader

**Abbreviations:** AYASHCN, Adolescents and Young Adults with Special Health Care Needs; MCHB, Maternal and Child Health Bureau; PMS, Portable Medical Summary; MI, Motivational Interviewing; HER, Electronic Health Record; HCT, Health Care Transition; IPACT, Intervention to Promote Autonomy and Competence in Transition-age Youth; SDT, Self-Determination Theory; AAP, American Academy of Pediatrics; AAFP, American Academy of Family Physicians; ACP, American College of Pediatricians.

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transition planning outcomes, which also include aspects such as provider availability, insurance limitations, and other psychosocial barriers.

Only 22.5 % of AYASHCN in the 2022 MCHB-sponsored National Survey of Children's Health were achieving the core transition outcome. While data from this survey should be interpreted given variations in measurement strategy over time,<sup>6</sup> this low percentage is worrisome and may be even lower for youth and families from diverse cultures. AYASHCN from households with a primary language other than English face added barriers to transition services.<sup>2,8</sup> The objective of this paper is to describe the development of a multi-level, multi-modal, dual-language intervention involving three key stakeholders – AYASHCN, caregivers, and providers – in order to facilitate meeting the three core elements of transition planning.

### 1.1. Alignment with theory and science

Self Determination Theory (SDT) posits that internal motivation and thus behavior is driven by three psychological needs: competence (i.e., skills, confidence), autonomy (i.e., control, choice), and relatedness (i.e., connection with supportive others).<sup>9</sup> SDT has substantial support from studies of long-term behavior change.<sup>9–14</sup> For example, perceived competence and physician support for autonomy (e.g., relatedness) were positively associated with health care transition (HCT) readiness among AYASHCN. Specifically, AYASHCN responded well to physicians who provided positive reinforcement for problem-solving and adopted a collaborative approach.<sup>15</sup> Those findings support the training of health care providers, in addition to AYASHCN and caregivers, to promote the adoption and facilitation of strategies for HCT preparation for AYASHCN and their families (with a focus on the primary caregiver). Cognitive science research supports the use of variation and spaced practice to improve information retention and knowledge development, suggesting the value of engaging AYASHCN through multiple formats spaced out over time.<sup>16</sup> Intervention strategies aligned with health behavior counseling are also the basis for techniques such as Motivational Interviewing,<sup>17</sup> which offers a proven set of interpersonal communication strategies for promoting behavior change.

### 1.2. AYASHCN preparation gaps

The MCHB has established HCT preparation as a national performance measure,<sup>18</sup> and the American Academy of Pediatrics (AAP), American Academy of Family Practice (AAFP), and American College of Physicians (ACP) recommend HCT preparation as part of routine care for all adolescents and young adults.<sup>19</sup> Meeting alone with the provider is endorsed by the AAP, AAFP, and ACP,<sup>19</sup> and increasing the proportion of adolescents speaking privately with a provider is an objective of Healthy People 2030.<sup>20</sup> Only 54 % of AYASHCN reported having time alone with their health care provider at their last preventive care visit.<sup>8</sup> Only 30 % of 17 year-olds with special health care needs reported meeting with providers alone, 41 % for those 18 or older.<sup>21</sup>

The MCHB core transition outcome also includes understanding changes in health care that occur at age of majority, typically 18 years of age, a focus of the AAP guidance as well.<sup>22</sup> There is evidence that AYASHCN prefer knowing about differences between child- and adult-centered care prior to transition.<sup>23</sup> Yet absent targeted education, AYASHCN and caregivers are unprepared to navigate shifts, such as transfer of responsibility for informed consent and medical decision-making and changes in access to medical records.

The Society of Adolescent Health and Medicine has endorsed using technology such as electronic health records (EHR) to strengthen the transition continuum of care and to ensure “the organization and transmission of high-quality information between the health care team and patients and families as well as between providers.”<sup>24</sup> Among the major barriers to transition to the adult care system reported by internists are: 1) difficulty in obtaining pediatric records and 2) AYASHCN

lack of preparation (ability) in accurately reporting their health history.<sup>25</sup> AYASHCN unable to report their health history to their adult provider risk inaccuracies with implications for reduced quality of care.<sup>26</sup> Hence, it is essential to equip AYASHCN to navigate EHRs and take advantage of available functionalities for sharing their health information.

There are health disparities in HCT planning for AYASHCN. Those who do not speak English have 2.5 times the odds of not achieving HCT preparation relative to English speakers. Individuals from minority populations are less likely than non-minorities to trust their providers.<sup>27</sup> During pediatric interviews, providers are less likely to direct questions about routine childhood illnesses to Black and Hispanic youth compared to White youth.<sup>28</sup> Reading comprehension and an understanding of mathematical properties (e.g. treatment A is 60 % effective and treatment B is 48 % effective) are vitally important to the health care informed consent process. Only 37 % of United States high school seniors are ranked as proficient in reading and 25 % in math.<sup>1</sup> These deficiencies constitute health illiteracy and have significant implications for interventions designed to improve autonomous health care self-management.

### 1.3. Caregiver preparation gaps

AYASHCN preparation for and success in HCT is influenced by the openness for transition of supportive others in their life, such as parents or caregivers. Caregivers who are able to monitor, be a resource, collaborate, and maintain ongoing dialogue are crucial to AYASHCN successfully transitioning to autonomous self-management. Yet many caregivers struggle with ceding control and nurturing autonomy in AYASHCN.<sup>29</sup> Forty-eight percent of caregivers reported difficulty with letting go of management responsibilities of their youth's medical condition.<sup>30</sup>

Locally, the genesis for a transition intervention to address these AYASHCN/caregiver knowledge gaps came from conversations with members of a hospital-based Caregiver Advisory Board who voiced concerns over not being prepared for abrupt changes when their AYASHCN turned 18 years of age. Specifically, caregivers reported feeling unprepared to lose access to their AYASHCN's electronic patient portal and to help their AYASHCN understand the concept of signing a consent for medical care. AYASHCN Advisory Board members voiced similar concerns about these perceived abrupt changes. While it is recommended that transition planning begin in early adolescence, it is critical that 17–18 year olds be prepared for changes at age 18 when they assume control of health care decisions.

### 1.4. Pediatric provider preparation gaps

Pediatric providers need better preparation to facilitate HCT.<sup>31</sup> AYASHCN have identified informational and skill-based needs that require provider support, including assistance with logistics and individualized management of their HCT process.<sup>26</sup> Consistent with SDT Theory, previous work has shown that provider support for autonomy is one of the two best predictors of transition readiness, the other being patient competence.<sup>15</sup> Yet many pediatric providers are ill-prepared to partner with AYASHCN or their families to plan or implement HCT.<sup>1,32</sup> Along with knowledge, pediatric providers need confidence in conveying HCT developmental tasks, such as inviting the caregiver out of the room and managing AYASHCN and caregiver responses to this invitation including surprise, uncertainty, and disagreement.

### 1.5. Evidence-based intervention gaps

Despite strong evidence that AYASHCN need preparation for HCT to the adult care system and agreement on the elements in planning that transition, evidence-based interventions to facilitate preparation of AYASHCN for successful HCT are lacking.<sup>7,33–37</sup> Few HCT intervention

studies have employed an experimental design<sup>38</sup> or used a comparison group.<sup>39</sup> There is a lack of rigorous research as to which methods improve the specific steps in HCT planning. No study has used a multi-level intervention targeting the three stakeholder groups that play critical roles in HCT preparation: AYASHCN, caregivers, and pediatric providers.

This paper describes the process of developing a HCT intervention for 17–18 year old AYASHCN, their caregivers and pediatric providers to address their knowledge and skill gaps simultaneously. Two prongs of the intervention, one targeted toward knowledge and process for AYASHCN/caregivers and a second prong targeted to pediatric providers will allow the intervention to meet the needs of all stakeholders. The stages of intervention development will be described, the components of the intervention will be presented with data provided from stakeholder feedback in the iterative process.

## 2. Methods

The research team used an iterative approach to generating content, structure, and the delivery format. Content generation and refinement were facilitated by weekly meetings of the multidisciplinary research team during which editing of intervention materials occurred. Intervention development included the following processes: 1) input from pediatric provider liaisons (“service liaisons”); 2) literature review; 3) existing patient educational material review; 4) development of a logic model; 5) development of specific intervention components; 6) input from AYASHCN and caregivers; 7) training for facilitators; and 8) practice and pilot testing with AYASHCN and caregivers. Human subjects were not recruited to participate in the intervention development phase of this funded project.

## 3. Results

The results section will report on the eight processes used in curriculum development, present the developed curriculum, and integrate data from feedback of key stakeholders.

### 3.1. Service liaison identification and input

The intervention was targeted to and developed in collaboration with four clinical services; Gastroenterology, Renal, Rheumatology, and Neurology. A liaison from each service was chosen based on previous

effective collaboration work with the research team. The research team met every other week with the liaisons to discuss all phases of the intervention planning to ensure the intervention fit their patient needs and clinic work flow. The liaisons (three physicians and a psychologist) were project collaborators with 5 % salary support.

### 3.2. Literature review

Literature searches in PubMed and PsycInfo used the search terms: health care transition education or readiness, chronic illness, adolescence, and provider intervention. This review also included searching updated citations for SDT related to health care outcomes. The research team reviewed current U.S. governmental and professional society HCT guidance (e.g., Society for Adolescent Health and Medicine, AAP, AAFP, ACP). The research team synthesized findings that identified gaps in meeting the MCHB core transition outcome, including results from prior empirical studies by the research team.<sup>21,40</sup>

The team decided to use a conceptual schema combining SDT constructs with a social-ecological approach (Fig. 1). Selected components of the social-ecological approach supplemented the SDT framework.<sup>24</sup> This perspective directs attention to the impact of patient characteristics (e.g., knowledge and attitudes), patient social environment (e.g., support from family), and the health care environment (e.g., clinic culture, patient-provider relationships, institutional processes such as those related to informed consent and the EHR, access to adult care providers) on the HCT process.<sup>25</sup>

### 3.3. Patient educational material review

HCT educational material was collected for potential inclusion in the intervention. Specifically, educational materials available from the EHR (Epic) used by the research team were reviewed for topics that addressed patient portal EHR access and function. Service liaisons provided condition-specific education materials.

### 3.4. Development of logic model

The processes outlined in Sections 3.1–3.3 were utilized as data to create a structured logic model<sup>41</sup> (Fig. 2). In the health sphere, logic models typically include inputs (prerequisites for program launch), activities (intervention components), outputs (factors that are targeted by the intervention in order to change or reinforce desired behaviors),

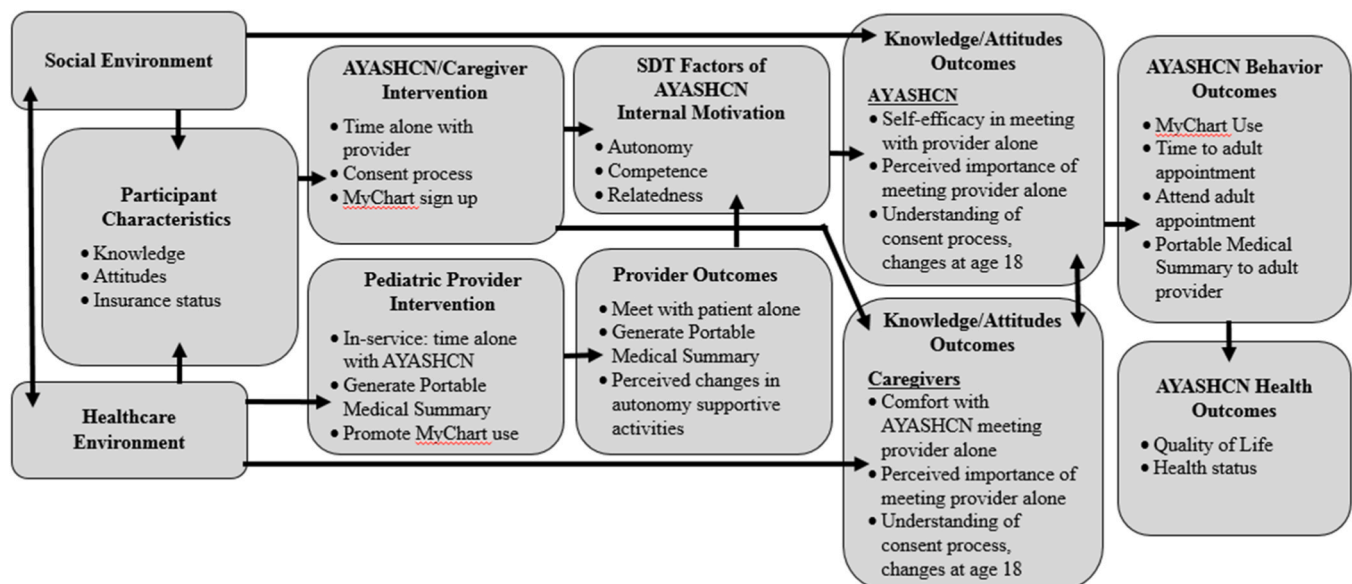


Fig. 1. Project IPACT Model.

Inputs	Activities	Outputs	Short-term Outcomes	Long-term Outcomes
<ul style="list-style-type: none"> <li>○ SDT framework and social-ecological model</li> <li>○ Motivational interviewing techniques</li> <li>○ Pediatric providers interested in learning how to help AYASHCN prepare to transition</li> <li>○ 17- and 18-old patients and their caregivers willing to participate in an intervention</li> <li>○ Facilities: clinic rooms, private space for virtual meetings</li> <li>○ Trained staff to deliver intervention</li> <li>○ Funding to conduct intervention</li> </ul>	<ul style="list-style-type: none"> <li>○ <u>Pediatric providers:</u> <ul style="list-style-type: none"> <li>○ Quarterly meetings with liaisons to solicit input and troubleshoot</li> <li>○ Group training session (guided by intervention manual with script, Powerpoint slides, video)</li> <li>○ Demonstration (how to generate portable medical summary)</li> <li>○ Reminders</li> </ul> </li> <li>○ <u>AYASHCN-caregivers:</u> <ul style="list-style-type: none"> <li>○ Periodic meetings with advisory boards to solicit input</li> <li>○ Pilot testing including opportunities for feedback</li> <li>○ Interactive sessions (guided by intervention manual with scripts)</li> <li>○ Pamphlets</li> <li>○ Videos</li> <li>○ Reminders</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ <u>Pediatric providers:</u> <ul style="list-style-type: none"> <li>○ Skills to invite caregivers out of the room</li> <li>○ Skills to support autonomy</li> <li>○ Relationship with AYASHCN and caregivers</li> <li>○ Efficient method to communicate patient care needs</li> </ul> </li> <li>○ <u>AYASHCN:</u> <ul style="list-style-type: none"> <li>○ Comfort communicating with provider and caregiver</li> <li>○ Experience meeting with provider alone</li> <li>○ Health care self-management skills</li> <li>○ Knowledge of changes at age 18 (health care decision making/consent, MyChart access)</li> <li>○ MyChart use</li> </ul> </li> <li>○ <u>Caregivers:</u> <ul style="list-style-type: none"> <li>○ Involvement</li> <li>○ Comfort letting go of control</li> <li>○ Support for autonomy</li> <li>○ Knowledge of changes at age 18 (health care decision making/consent, MyChart access)</li> </ul> </li> <li>○ <u>System:</u> <ul style="list-style-type: none"> <li>○ Institutional support for HCT</li> <li>○ Secure EHR with patient-facing web portal</li> <li>○ Access to adult care providers</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ <u>Pediatric providers:</u> <ul style="list-style-type: none"> <li>○ Invite caregiver out of the room</li> <li>○ Engage with AYASHCN about health care self-management and HCT</li> <li>○ Generate portable medical summary</li> <li>○ Respond to AYA MyChart message</li> </ul> </li> <li>○ <u>AYASHCN:</u> <ul style="list-style-type: none"> <li>○ Meet with provider alone</li> <li>○ Communicate relevant health information to caregiver</li> <li>○ Provide informed consent for health care</li> <li>○ Register for and use MyChart</li> <li>○ Access and use portable medical summary</li> <li>○ Attend adult appointment within recommended time frame</li> </ul> </li> <li>○ <u>Caregivers:</u> <ul style="list-style-type: none"> <li>○ Generate plan for communicating about provider visit</li> <li>○ Agree to step out of the room to allow AYA to meet with provider alone</li> <li>○ Ask questions before giving advice</li> <li>○ Encourage and/or reinforce self-management</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ Health maintained during transition to adult care</li> <li>○ Health-related quality of life</li> <li>○ Global health and well-being</li> <li>○ Successful HCT to adult based-care, as defined by MCHB</li> </ul>

**Fig. 2.** Logic model for multi-level, multi-modal intervention to promote autonomy and competence in transition-age AYASHCN (IPACT).

short-term outcomes (the specific behaviors the program is designed to change or reinforce, which are often the focus of evaluations to determine program success), and long-term outcomes (the ultimate health outcomes sought).

Inputs of this study's logic model (Fig. 2) include circumstances and resources outside of the intervention implementation that are necessary for success, such as theoretical framework, logistical considerations with funding source, and availability of willing providers, caregivers, and AYASHCN. Activities include feedback-informed, separate interventions for pediatric providers and AYASHCN-caregiver dyads. Outputs and short-term outcomes are separated with respect to pediatric providers, AYASHCN, caregivers, and system-level considerations. Short-term outcomes are related to intervention-promoted behaviors (e.g., provider and AYASHCN meeting alone, increased communication between caregiver-AYASHCN dyad and provider-AYASHCN dyad) and longer-term behaviors (e.g., attendance at adult-care appointment). Long-term outcomes are broader hypothesized outcomes projected to improve as a result of the intervention, including maintenance of health and related quality of life.

### 3.5. Development of specific intervention components and intervention map

Building on the research team's experience with the development of HCT interventions<sup>42,43</sup> and the findings from the literature and educational materials review, the research team and liaisons concluded that the optimal intervention would be multi-modal. Accordingly, the research team developed curriculum components in three

complimentary formats: 1) interactive skill building sessions (facilitated discussion or presentation with discussion); 2) videos; and 3) informational pamphlets. The resulting intervention was named the Intervention to Promote Autonomy and Competence in Transition-age Youth (IPACT).

#### 3.5.1. IPACT intervention development for AYASHCN/caregiver

The team decided the intervention would target the AYASHCN and caregiver together to allow for mutual learning and support in a discussion-based format. A facilitator manual for interactive skill building sessions was created first, followed by scripts for the accompanying videos and then the pamphlets provided for each session. The video scripts and pamphlets were developed by the research team and the facilitator manual was developed by one research team member. Four team members of different disciplines (e.g., medicine, psychology, law, and a research coordinator who was a young adult with lived experience), plus the service liaisons, independently reviewed these materials and suggested edits. The final edits were made in team meetings after reaching consensus. Video scripts were reviewed with a video production company, which was contracted to refine the messaging, shoot the videos, and edit/format the final video products. To provide access to AYASHCN whose family identify as preferring communication in Spanish, video scripts and pamphlets were translated using a professional translation service, subtitles were added to videos, and a facilitator who speaks Spanish approved the interactive skill building session content.



3.5.2. IPACT intervention map for AYASHCN/caregiver

The AYASHCN-caregiver portion of IPACT includes three interactive skill building sessions, spaced approximately every six months starting around an AYASHCN's age of 17 years. The first two sessions are implemented prior to the AYASHCN's 18th birthday; the third session is implemented after the AYASHCN's 18th birthday. Sessions are 45 min in length. Following the first and second interactive skill building sessions, AYASHCN and caregivers are provided with a video to watch and a pamphlet to review prior to the next session. Fig. 3 represents the timing and components of the full IPACT intervention.

Each of the three AYASHCN-caregiver sessions focuses on one major HCT skill. Session 1 focuses on communication strategies in two situations: meeting alone with a provider and relaying information from time alone with the provider to the caregiver. Session 2 focuses on the significance of consenting for services and understanding the legal implications of turning 18 years old on health care delivery. Session 3 focuses on the rationale and specific skills for navigating the EHR patient portal (Epic's MyChart). Content for each finalized component of AYASHCN-caregiver intervention is presented in Table 1.

3.5.3. IPACT intervention development for pediatric providers

Concurrently, the interactive skill building sessions for pediatric providers were created by an identified medicine lead. The same process for review and edits, as described in 3.5.1, was completed by the research team/liasons and an accompanying video script was created, reviewed, and filmed to support the provider presentation. No pamphlet was created for pediatric providers.

3.5.4. IPACT intervention map for pediatric providers

This portion of IPACT includes two, 1-hour interactive didactic sessions on HCT planning followed by provider-initiated problem solving led by a medicine faculty research team member as well as one accompanying video. This training intervention is intended to be conducted in a group format. The first provider interactive skill building session discusses the AYASHCN meeting with the provider alone, promoting and supporting the patient's self-management, and discussing eventually seeing an adult provider. The providers watch the instructional video, modeling two scenarios: 1) the caregiver willingly leaving the room; and 2) the caregiver being reluctant to leave the room, and how the provider handled each scenario. The video then models a provider interviewing an AYASHCN about self-management and how to

navigate the likelihood of drinking alcohol and if that might impact their chronic condition. This video presentation is followed by active problem solving for barriers or clinical situations which may make inviting a caregiver out of the room challenging. Session 2, implemented 3–4 months after the first session, demonstrates how to access and generate the portable medical summary within the EHR, followed by the provider teaching back how to access and generate the portable medical summary. Content for the interactive skill building sessions and video are presented in Table 2.

3.6. AYASHCN and caregiver input

As the intervention was developed, the research team repeatedly solicited and incorporated feedback on all intervention components (e.g., clarity and acceptability in wording, interactive skill building session examples, use of visuals during interactive skill building session) from separate AYASHCN and caregiver Hospital Advisory Boards along with other AYASHCN and caregivers receiving care at the research team's institution. Caregiver and AYASHCN reviewed each modality (e.g., watched the video, experienced the script, read the pamphlet). The research team created open ended questions to inquire about content detail and relevance, presentation of content, and readability. As a specific example, the advisory boards were asked to review specific situations presented in the materials and offer additional details to increase relevance to youth and families. Each advisor was compensated \$25 per hour. Combined results of stakeholder feedback are presented in Section 3.8.

3.7. Facilitator training

Research team members were facilitators of the patient and caregiver interactive skill building sessions. They were trained to lead each session using patient-centered and health behavior change strategies (e.g., Motivational Interviewing) by one of the authors.<sup>17</sup> Facilitators used agreed-upon facilitator notes and clinical examples in the manual to ensure standardization of material presented.

With respect to the process/delivery of the interactive skill building session, specific language was discussed, practiced, and formally written into the facilitator manual to provide facilitators with a conversation process for supporting motivation on behavior changes presented in the interactive skill building sessions. Examples of behavioral changes

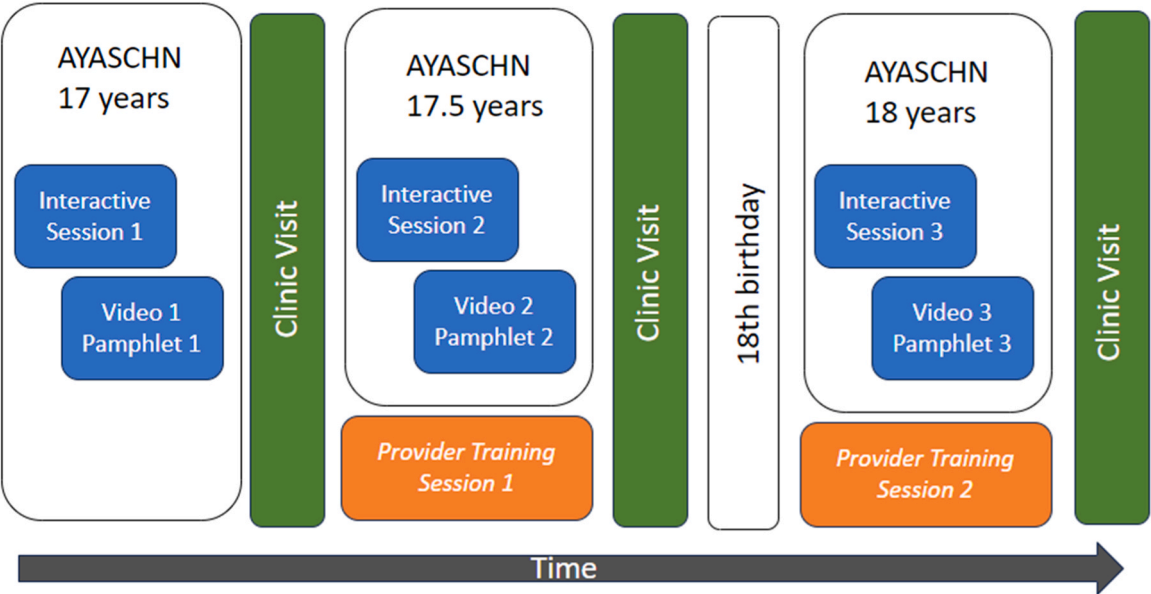


Fig. 3. IPACT Intervention Map.

**Table 1**  
AYASHCN and caregiver intervention curriculum outline.

AYA age	Major Objectives/Activities
17 y/o	<p><u>Interactive Session 1: Communication strategies and meeting alone with a provider</u></p> <ul style="list-style-type: none"><li>• Identify family's goals for attending intervention</li><li>• Discuss the planned shift to AYASHCN responsibility for medical care, and the changing role of the caregiver during this developmental time</li><li>• Discuss the rationale and benefits of AYASHCN spending time alone with their provider</li><li>• Model and practice strategies for asking and answering questions from the provider</li><li>• Create expectations and communication strategies for sharing medical information and well-being between AYASHCN and caregiver</li><li>• Describe and model communication strategies between caregiver and AYASHCN for sharing medical information, with a focus on specific skills before and after a medical visit. Examples:<ul style="list-style-type: none"><li>o Caregivers using open-ended questions to plan for upcoming visit with provider</li><li>o Planning a specific time for information sharing between caregiver and AYASHCN after a visit</li><li>o Strategies for AYASHCN remembering topics to address with provider alone</li></ul></li></ul> <p><u>Video presents vignette of</u></p> <ul style="list-style-type: none"><li>• AYASHCN and caregiver sharing details with a provider</li><li>• Provider modeling asking the caregiver out of the room</li><li>• Preparation for transition to adult healthcare and AYASHCN answering questions about their healthcare plan</li><li>• AYASHCN modeling asking question to provider</li><li>• AYASHCN modeling making a follow-up appointment together and discussing the content of the session</li></ul> <p><u>Pamphlet emphasizes AYASHCN communication strategies with providers, specific ways a caregiver can begin to gradually shift teen responsibility for some tasks, benefits of AYASHCN speaking alone with their provider, communication strategies and examples for sharing healthcare information after a clinic visit</u></p>
17.5 y/o	<p><u>Interactive Session 2: Consent for treatment process and legal implications when turning 18</u></p> <ul style="list-style-type: none"><li>• Define and identify significance of understanding consent for services after age 18</li><li>• View sample administrative documents commonly signed during check-in for appointment</li><li>• Understand the process of AYASHCN signing consent for treatment</li><li>• Discuss role of caregiver as support, highlighting caregivers as available during and after HCT to adult care</li><li>• Introduce patient portal of EHR (MyChart) and provide sign-up information in preparation for AYASHCN's 18th birthday</li></ul> <p><u>Video presents vignette of clinical changes in the following areas</u></p> <ul style="list-style-type: none"><li>• Check in / front desk communication</li><li>• Clinic visit and speaking with a healthcare provider alone</li><li>• Health care decision making</li></ul> <p><u>Pamphlet emphasizes important documents to bring to a clinic visit, the purpose for being asked to arrive to an appointment early, what changes in the check in process to prepare for after an AYASHCN turns 18, the definition of a consent form, the continued support of caregivers even after legal responsibilities shift, reminder to set up MyChart account after 18th birthday and before next IPACT session.</u></p>
18 y/o	<p><u>Interactive Session 3: Utilizing patient portal of EHR: Rationale and Skills</u></p> <ul style="list-style-type: none"><li>• Provide MyChart tutorial focused on<ul style="list-style-type: none"><li>o Scheduling and accessing current appointments</li><li>o Accessing immunization records and lab results</li><li>o Viewing Portable Medical Summary (PMS)</li><li>o Refilling a prescription</li><li>o Messaging a provider</li></ul></li><li>• Review communication strategies and expectations for communication discussed by family</li><li>• Engage in problem solving skills, as needed, for identified barriers</li></ul> <p><u>Video presented a didactic presentation with voice over re-demonstrating each of the five MyChart components from Interactive Session 3. Pamphlet emphasizes process of sharing one's medical record with important others, skills for using MyChart to communicate with providers, summaries of Test Results, Health Summary, and Medications tabs in MyChart, utilizing the pre-check in feature, an affirming statement highlighting completion of IPACT program.</u></p>

**Table 2**  
Provider Intervention Curriculum Outline.

Timeframe	Major Objectives/Activities
Interactive Session 1	<ul style="list-style-type: none"><li>• Provide an overview to the study design and AYASHCN-caregiver intervention</li><li>• Teach an overview of MCHB standards for healthcare transition planning</li><li>• Explain different components of AYASHCN self-management</li><li>• Provide rationale for spending time alone with an AYASHCN in a clinic visit</li><li>• Model asking a caregiver to step out of the room</li><li>• Model discussing a sensitive topic with an AYASHCN and supporting their engagement in the conversation</li><li>• Host a discussion on challenges to inviting a caregiver out of the room and solutions to those challenges</li></ul>
Interactive Session 2	<ul style="list-style-type: none"><li>• Lead problem solving session for challenges and solutions with inviting a caregiver out of the room that emerged since last training session</li><li>• Review content from AYASHCN intervention of MyChart communication with their provider in order to support messaging from provider about appropriate, individualized clinical uses for MyChart messages</li><li>• Teach components of the PMS</li><li>• Demonstrate accessing the PMS in EHR, with interactive teach-back to review skill development</li><li>• Provide reminder that providers will receive a list of study participants to remind them to interview them alone at each visit and to generate the PMS at the 18yo visit</li></ul>

included both immediate tasks (e.g., watching the accompanying video or reading the pamphlet before the next interactive skill building session) and integration of health behaviors to carry forward related to the intervention content (e.g., the AYASHCN asking the provider a question at the next clinic appointment, sending a message to the provider in the EHR patient portal). Aligned with SDT and with health behavior counseling strategies (e.g., Motivational Interviewing),<sup>17</sup> the intervention included asking AYASHCN and their caregiver about their motivations for joining the study and for attending the sessions, personal goals for transition, and accomplishments in the process of HCT. These questions were coupled with reflective listening skills, especially with a focus on change talk to: 1) increase engagement from families; 2) model and affirm listening and communicating skills for families and AYASHCN; while also 3) personalizing intervention.

3.8. Practice and pilot testing

Practice administrations of the IPACT interactive skill building sessions were first conducted with research team members. Then, the IPACT components targeting AYASHCN/caregivers were pilot tested with 1–2 sets of AYASHCN-caregiver dyads per component (e.g., interactive skill building sessions, videos, pamphlets), with a total of nine AYASHCN and seven caregivers providing feedback. The provider training session was again practiced within the research team and edited by the research team.

3.8.1. Stakeholder feedback for the provider intervention

Service liaisons reviewed the interactive skill building session content and video scripts. They were supportive of the intervention and affirmed that the plan for the pediatric provider interactive skill building sessions was focused on inviting the caregiver out of the room. Example feedback for the perceived utility of the content on inviting the caregiver out of the room included describing this process as in the patient's best interest. Positive feedback was focused on the instruction and modeling of how to invite the caregiver out of the room. Service liaisons reviewed the AYASHCN-caregiver video script to ensure it was congruent with the types of interactions they had with their patients. Scenes from the AYASHCN-caregiver video script were then used in the provider intervention video script.

Identified improvements reported by the service liaisons are

described in Table 3. As an example of the video script review, service liaisons made wording suggestions aligned with SDT framework for maximizing AYASHCN engagement. The example below highlights changes from before and after review in a provider’s response to a patient’s question about interactions between medications and alcohol:

Before.

Health care provider: That’s a great question. While there’s not any direct interaction with your medications, I would encourage you to think about the other negative effects of drinking, like getting in trouble if you get caught drinking underage, or not being in control and making poor decisions.

After.

Health care provider: That’s a great question. There’s no known interaction with your medications. Drinking alcohol is part of college life and you may choose that it is not part of your lifestyle. However, have you thought about who you could talk to about this and how you’ll handle it?

3.8.2. Stakeholder feedback for the AYASHCN/caregiver intervention

Feedback provided by AYASHCN and caregivers during advisory board meetings and during pilot testing was evaluated across each mode (video, pamphlet, session manual). Comments were organized with respect for the stakeholders’ perceived value of the content/positives of the intervention and the perceived improvements/suggestions for both content and delivery. See Table 4. The research team incorporated this feedback into the final versions of the interactive skill building session facilitator manual and pamphlets.

4. Discussion

This paper describes the development of a multi-level (AYASHCN/caregiver, provider), multi-modal (interactive skill building sessions, videos, pamphlets), bilingual (Spanish, English) intervention designed to increase a set of specific self-management strategies universal to a majority of AYASHCN transitioning to adult-based care. Specific self-management strategies include AYASHCN meeting alone and engaging in health care dialogue with a provider; caregivers and providers fostering this time alone with acceptance and reinforcement; AYASHCN communicating with caregivers about health-related changes; and AYASHCN and caregivers knowing and increasing comfort with changes in consent, release of information, and communication via EHR that occur after an AYASHCN turns 18. Unique to this intervention model are the multi-modal intervention strategies (e.g., interactive skill building sessions, written materials, video presentation) that are provided to all key individuals responsible for helping to support an AYASHCN (e.g., AYASHCN, caregiver, provider). The creation of complementary

Table 3  
Service liaison feedback for provider intervention components.

Component	Content valued	Delivery details (preferences/ advice)
Interactive sessions and videos	<ul style="list-style-type: none"><li>o Use of examples of caregivers not wanting to leave the room</li><li>o Instructions on how to generate a portable medical summary</li></ul>	<ul style="list-style-type: none"><li>o Ensure that videos and other materials speak to patients with different or uncertain future plans (e.g., college, work)</li><li>o Provide additional examples of how providers handle patient or caregiver pushback to the caregiver leaving the room</li><li>o Make the video available to providers after the training</li><li>o The patient should give a summary of the meeting with the provider to both the caregiver and the provider</li></ul>

Table 4  
AYASHCN-caregiver feedback on IPACT intervention.

Component	Content valued	Delivery details (preferences/advice)
Interactive sessions	<ul style="list-style-type: none"><li>o Need for independence</li><li>o Comfort with the teen meeting with the provider alone</li><li>o Process of signing a General Consent for Treatment Form when teen turns 18</li><li>o Caregiver will lose MyChart proxy access when teen turns 18, and resulting feelings from caregivers about losing MyChart access for their child.</li><li>o Use of MyChart to access lab results, immunization records, and the Portable Medical Summary, join waitlist for appointments, and share medical records</li></ul>	<ul style="list-style-type: none"><li>o Keep sessions brief</li><li>o Piggyback on clinic visits</li><li>o Send reminders one week prior and one day prior to clinic visit</li><li>o Share video/pamphlet before session</li><li>o MyChart visuals helpful in processing information</li><li>o Teen and caregiver may have different levels of comfort with research team member guiding them through actual MyChart account on teen’s phone</li><li>o Prompt teen to activate MyChart account before session to avoid confusion</li></ul>
Pamphlets	<ul style="list-style-type: none"><li>o Normalization of transition process and message that becoming an adult is exciting</li><li>o Specific examples of communication strategies and questions</li><li>o Reassurance to allay caregiver fears of being cut out of relationship/visit</li><li>o Encouragement of reciprocity between parent and teen (e. g., prompting both to express gratitude)</li><li>o Support for teen in planning for and scheduling appointments</li><li>o Recap of information about sharing medical records</li><li>o Wrap-up on the back of the pamphlet</li></ul>	<ul style="list-style-type: none"><li>o Make headers specific and appealing to teens</li><li>o Avoid “kiddish” icons</li><li>o Font size shouldn’t be so small that text is difficult to read</li><li>o One teen who didn’t like reading said to limit text to main points in simple language, but another found it helpful to have everything you need to know to transition</li><li>o Share during interactive session as a visual aid</li></ul>
Videos	<ul style="list-style-type: none"><li>o Rationale for teen meeting with provider alone</li><li>o Caregiver development of comfort with teen meeting with provider alone/good example of caregiver role</li><li>o Teen self-management skills, including teen comfort in meeting with provider alone and how to ask questions, manage medications, and share medical history with new provider</li><li>o Use of MyChart to make appointments</li><li>o Information about timing of transition to adult care system (e.g., don’t immediately lose access to pediatric specialists upon turning 18)</li></ul>	<ul style="list-style-type: none"><li>o Keep brief and straightforward</li><li>o Helpful “booster” after interactive session</li><li>o Keep sections using PowerPoint slides short and make sure slide backgrounds look up-to-date and appealing</li></ul>

interventions designed for all three key stakeholders allows for targeted and focused practice of specific skills and recognizes each stakeholder’s role in teaching and reinforcing these behavioral and knowledge changes.

This intervention and the process of its development recognizes that self-management is a cornerstone of successful HCT preparation and requires knowledge and skill acquisition by all three stakeholder groups (AYASHCN, caregiver, provider) in that preparation. The intervention model is founded on well-established SDT and social-ecological constructs and provides a logic model wherein AYASHCN, caregiver and

provider knowledge and skill gaps are addressed simultaneously using patient-centered processes of communication. Stakeholders informed the development of the intervention and affirmed the resulting curriculum's content and process. The AYASHCN/caregiver components of IPACT have been translated into Spanish. This represents the first multi-modal, multi-level, dual language intervention to improve HCT and meet the three key elements of the MCHB core transition outcome.

Specifically, this intervention brought together four specialties in pediatric care to create an intervention functional for each specialty. While this team recognizes that there are specific disease components that are unique to a patient's self-management success, the components of this stakeholder-approved intervention represent a generalizable practice model of specific self-management skills necessary for a large majority, if not all, AYASHCN during their transition to adult-based care. In addition, this intervention would attend to self-management skills appropriate for an adolescent without a current chronic illness. While not inclusive of all necessary self-management skills, the skills provided in this intervention go beyond that of knowledge to include both skills-based practice as well as each family creating and practicing their own communication strategies for health care. The communication strategies discussed with AYASHCN in this intervention could generalize to many types of young adult conversations. The creation of this model that focuses on a subset of universal skills related to adult health care transition allows for a potentially cost-effective and hospital-wide application.

The implications for clinical care in pediatric settings are significant in that if found to be effective, the curriculum has the potential to impact AYASHCN, caregiver and provider roles at the level of the clinic visit. In doing so, it could provide all three sets of stakeholders a path forward in the inevitable transition to adult-based care, representing a culture shift in pediatric practice. Few HCT intervention studies have employed an experimental design<sup>38</sup> or used a comparison group.<sup>39</sup> There is a lack of rigorous research as to which methods improve the specific steps in health care transition planning. A next step is to conduct a rigorous evaluation of the IPACT intervention to evaluate its feasibility, acceptability, and efficacy and collect additional stakeholder feedback toward further improvements. Using a quasi-experimental design, 17-year-old adolescents and their caregivers from four clinical services, and their providers, will be recruited to participate in the IPACT intervention. A group of 18-year-old patients seen by these same providers a year earlier will serve as historical controls. Potential AYASHCN measures include knowledge of changes in medical decision-making at age 18, perceived competence in managing health care, and the SDT constructs of health care autonomy, parent/caregiver and provider support for health care autonomy,<sup>15</sup> self-efficacy to meet with the provider alone, and perceived importance of meeting with the provider alone. Likely provider measures include: percent of visits wherein AYASHCN meet with the provider alone, changes in perceived importance of engaging in autonomy supportive behaviors, and perceived engagement in autonomy supportive behaviors.<sup>40,44</sup>

#### 4.1. Limitations

Content of the intervention demonstrated applicability and garnered positive feedback from AYASHCN, caregivers, and service liaisons. While this demonstrated an important generalizability across services treating different chronic conditions, the intervention was tailored for the specific institution. Edits based on institution-specific standards (e.g., adolescent patient portal access, specific consent forms and processes, and specific EHR utilized) would need to be made to tailor the intervention to successful HCT transition from a different institution. Further, the intervention content did not address the changing nature of insurance coverage during this period of transition as well as the impact of changing employment status on insurance. This could be a significant barrier to accessing health care, self-management of chronic illness, and of learning and implementing the strategies of self-management for

transition to adulthood. Just as the content may need to be adjusted for institutional processes as noted above, further adaptation of this intervention in other settings may need to add examples for navigating specific insurance-specific barriers known to that population. Last, during intervention development, the process did not use a librarian for the literature review.

The framework and intervention described above have the potential to improve health care transitions across a variety of conditions and settings. However, rigorous evaluation will be necessary to demonstrate that potential. In addition, interventions for subpopulations of AYASHCN with distinctive features impacting cognition and communication, such as AYASHCN with intellectual disabilities or some autism spectrum disorders, will need to be tailored to the particular capacities and needs of those subpopulations.<sup>45,46</sup> Last, the socio-ecological model includes additional, important constructs, such as the influence of peers or extended family members or the larger cultural context in which families are embedded which were not the focus of this project.

## 5. Conclusions

The work described in this manuscript represents a testable multi-level intervention for AYASHCN/caregivers and pediatric providers to assist with three HCT behaviors associated with healthy transition outcomes. These three behaviors include communication strategies between all three stakeholders (e.g., provider inviting a caregiver out of the room, AYASHCN sharing health information with family, caregiver allowing space for AYASHCN communication with provider while also modeling important behaviors, such as informed consent, AYASHCN practicing communication in person and electronically regarding health). This intervention offers a multi-modal approach that combines in person/virtual sessions, videos, written information, with material available in both English and Spanish. This intervention addresses the recognized gaps in all three stakeholder groups that must be filled simultaneously in order for HCT to have a chance to succeed and the resultant quality of life and health status achieved.

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## Ethical statement

Human subjects were not recruited to participate in the intervention development phase of this funded project.

## CRedit authorship contribution statement

**Hergenroeder C. Albert:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Conceptualization. **Babla Jordyn:** Writing – review & editing, Project administration, Investigation, Data curation. **Blanca Sanchez-Fournier:** Writing – review & editing, Project administration, Investigation, Data curation. **Constance M. Wiemann:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **Mary Majumber:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Beth H. Garland:** Writing – review & editing, Writing – original draft, Supervision, Project



administration, Methodology, Funding acquisition, Conceptualization.

## Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work the authors did not use any Generative AI and AI-assisted technologies in the writing process.

## Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Funding from Global Health Therapeutics to pilot an adaptation of this intervention in adolescents with sickle cell diagnosis.

## Data availability

No data was used for the research described in the article.

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## Data sharing statement

De-identified individual participant data will not be made available.

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