Webinar # 5
Youth, Young Adult, and Parent Engagement

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Got Transition’s Webinar Series Goals

• Support state Title V implementation and measurement of health care transition (HCT) in care coordination programs

• Guide care coordination improvements by sequentially building on the evidence-informed Six Core Elements

• Share promising practices from state Title V-supported care coordination programs (CC)

• 5-session webinar series on HCT and care coordination

• The webinars and handouts will be available following each session at www.gottransition.org/webinars
Webinar #5: Youth/Young Adult and Parent Engagement

Objectives

At the conclusion of Webinar 5, attendees will be able to...

• Understand the youth/young adult/parent engagement levels in the Six Core Elements of HCT

• Identify parent/family and youth engagement frameworks or models

• Discuss opportunities and principles for involving and providing support to youth/young adults/parents in HCT care coordination initiatives

• Become familiar with Got Transition resources for youth, young adults, and parents

• Learn about Wisconsin Title V’s examples of engaging youth and parents in HCT efforts
Webinar #5 Handouts

- Webinar #5 Slideshow
- Got Transition's “Questions to Ask Your Doctor about Transitioning to Adult Health Care,” “Transition Feedback Survey for Youth,” “Transition Feedback Survey for Parents/Caregivers,” online quiz and social media toolkit
- Wisconsin’s CYSHCN Resources: Health Transition Wisconsin, Annotated Transition Resources, Presentation Links
Webinar #4
Review: Integration into Adult Care

• Support the development of HCT Policy/Welcome and FAQs information by the adult practice(s) who will accept young adults (YAs) and share this info with pediatric practice(s) to share with their YA

• Facilitate the initial appointment to the adult clinician including confirmation of receipt of the transfer package and covering the youth during the bridge time to the adult appointment

• Discuss Indiana’s Title V-funded Center for Youth and Adults with Conditions of Childhood in their support of YA’s who are transferring, adult clinicians integrating YA into their practice, and linking to adult disability resources
Webinar #3
Review: Transfer to Adult Care

- Identify ways for identifying adult primary and specialty providers
- Understand an adult model of care & Got Transition resources
- Understand contents of transfer package to send to adult provider
- Identify ways to communicate with and support adult practices (e.g., care coordination support)
- Learn how KY and MD care coordination programs plan and support transfer to adult care
Webinar #2 Review: Transition Preparation

- Review of Six Core Elements: Transition Policy, Tracking, Readiness Assessment, Planning
- Options for Customizing HCT Tools/American College of Physician’s HCT efforts
- DC’s Parent Navigator Program at Children’s National Health System’s customization and use of Six Core Elements
Webinar #1
Review: Starting a Transition Improvement Process Using the Six Core Elements

- HCT clinical foundations: AAP/AAFP/ACP Clinical Report & Six Core Elements
- HCT performance measurement options
- Title V Care Coordination baseline results from Current Assessment of HCT
- Starting a HCT pilot using quality improvement methods and writing an aim statement
Baseline Assessment of HCT Implementation in CC Programs: Youth and Family Engagement

Level 1. CC program offers general information about HCT to YSHCN and parents, but has limited involvement of YSHCN and parents in Title V HCT program development and evaluation.

Level 2. CC program, in addition to its HCT education efforts with YSHCN and parents, has trained YSCHN and parent leaders about Six Core Elements.

Level 3. CC program offers HCT education to YSHCN and parents, has training of YSHCN and Parents about 6CE, and involves them in Title V HCT program development and evaluation.

Level 4. CC program offers HCT education to YSHCN and parents and involves them as HCT leaders, knowledgeable about 6CE, in statewide efforts to advance HCT improvements.
Got Transition's 2017 baseline results on youth and family engagement from 28 reporting states (out of 32 that selected HCT as a national performance measure):

- Average score: 1.6
- 26 states scored at levels 1 or 2
- 2 states scored at levels 3 or 4 (Kentucky and Indiana)
Aim for Improvement

• State Title V-supported care coordination programs may want to consider adding a new HCT measurable strategy/aim going forward

• Increase the level of youth and family engagement in HCT from the state's baseline results (level 1 or 2) to level 3 or 4 in care coordination programs.
Framing Youth and Family Engagement in HCT

Mallory Cyr, MPH
Health Care Transition Consultant
Member, Got Transition’s Cabinet Executive Team
What does it take to establish authentic and meaningful engagement?

- Time
- Support & training
- Patience
- Flexibility
- $$$
- Buy-in/Leadership
Framing Parent/Family Engagement

Two important frameworks:

1. Eileen Forlenza’s Progression of Leadership for Families (handout)
   - **Inner Ring:** e.g., work with family to develop service plan, offer classes on self empowerment
   - **Community Ring:** e.g., work with family leaders to develop training, include families in developing feedback mechanisms
   - **Outer Ring:** e.g., empower family leaders to recommend policy changes, provide leadership development opportunities for families,
Framing Parent/Family Engagement

2. Family Voices/Lucile Packard Foundation's Framework for Assessing Family Engagement in Systems Change (handout)

- **Representation:** Reflect diversity of community (age, ethnicity, income, education, geography); Partner with family-led and community-based organizations
- **Transparency:** Provide access to relevant knowledge; Practice partnership in all parts of process
- **Impact:** Identify what has changed and what organization or system of care is doing differently because families were involved
- **Commitment:** Promote engagement as core value; Establish engagement at all levels in all systems of care
Framing Youth/Young Adult Engagement

Two important frameworks:

1. Roger Hart’s Ladder of Participation

Rung 1. Manipulation: Adult-led activities, in which youth do as directed without understanding purpose of activities

Rung 2. Decoration: Adult-led activities, in which youth understand purpose, but have no input in how they are planned

Rung 3. Tokenism: Adult-led activities, in which youth may be consulted with minimal opportunities for feedback

Rung 4. Assigned, but informed: Adult-led activities, in which youth understand purpose, decision-making process, and have a role

Rung 5. Consulted and informed: Adult-led activities, in which youth are consulted and informed about how their input will be used and the outcomes of adult decisions

Rung 6. Adult initiated shared decisions with youth: Adult-led activities, which decision-making is shared with youth

Rung 7. Youth initiated and directed: Youth-led activities with little input from adults

Rung 8. Youth initiated shared decisions with adults: Youth-led activities in which decision making is shared between youth and adults working as equal partners
Framing Youth/Young Adult Engagement

2. School-Based Health Alliance “Youth Engagement Toolkit”
http://www.sbh4all.org/training/youth-development/youth-engagement-toolkit/

Youth Participation Models:

- **Youth-Led:** Y/YA are main spokespersons and look to adults to provide administrative support
- **Youth-Adult Partnership:** Y/YA/Adults are equal partners in developing a common agenda
- **Adult-Led:** Adults seek out Y/YA as core constituents
Six Core Elements and Y/YA/Family Engagement

- **Transition Policy:** Develop policy with input from youth and families
- **Transition Readiness:** Discuss with youth and parent/caregiver their needs and goals and jointly develop goals and prioritized actions
- **Transition Planning:** Prepare youth and parent/caregiver for an adult approach to care, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information; plan with youth and families about timing and preferences for transfer to adult provider
- **Transfer Completion:** Elicit feedback from youth, young adults, and parents about experience with transition process
- **Current Assessment of HCT Activities:** Measures levels of youth and family feedback and youth and family engagement
Got Transition’s National Young Adult Transition Advisory Group

- 12 YAs with and without disabilities, all 18-25 years old
- Representing various national and state health-related organizations
- Quarterly calls to assist GT with developing messaging to Y/YA about improving transition to adult care and accessing care and coverage
- Helped develop Health Care Transition Online Quiz
- Helped with Social Media Toolkit development and ongoing dissemination
Young Adult Transition Messages

- **Why My Health?:** I choose to take care of my health/manage my own health because...

- **WIIFM:** What's in it for me? At the end of the day we ALL do things for a reason. What's in it for you to take charge of your health?

- **Take Charge of Your Life, Take Charge of Your Health:** It can be empowering to be your own advocate, even if it can be overwhelming. This could be a stepping stone to talk about steps in transition that make a young adult feel empowered.

- **Changing Roles:** Talk about a time you took over a responsibility
Young Adult HCT Online Quiz

- Asks key questions to help YAs prepare for changes that happen usually between 18 and 22
- Includes tips and linked resources to support YAs to be self-advocates
- LINKS: bit.do/HCTquiz OR gottransition.org/youthfamilies/HCTquiz.cfm
Social Media Toolkit

- Includes YA-specific sample Facebook posts, tweets, newsletter entries, and downloadable graphics and memes
- Promotes the Health Care Transition Quiz and the messages developed by the National YA Advisory Group
- Encourage YAs to transition to adult care, to take on more responsibility for their health care, and to access care regularly

Available at http://gottransition.org/resourceGet.cfm?id=464
Wisconsin Title V Efforts

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Wisconsin Children and Youth with Special Health Care Needs

Maia Stitt, MS
Youth Health Transition Initiative Coordinator
Waisman Center
Wisconsin CYSHCN Network

- Parent Parent Wisconsin
- Family Voices of Wisconsin
- Wisconsin Medical Home Children’s Health Alliance of Wisconsin
- ABC for Health Since 1994
- Wisconsin Title V Children and Youth with Special Health Care Needs Program
- Health Transition Wisconsin Supporting Youth to Adult Healthcare
Tools and Resources

- Checklists and Skill Building
- Pocket Guide
- Learning Community
- Wisconsin Regional Centers
- Education and Awareness Events
- Website

https://healthtransitionwi.org/
Youth and Families

- Encourage Wisconsin’s youth and their families to make individual choices to enhance their health and well-being.

- Provide Wisconsin and national health transition tools and resources.

- “Build Your Bridge” trainings.
Partner with health care systems, providers, and the community to share health transition tools and resources statewide.

Support practices and health care systems to initiate processes to increase awareness and skills that encourage successful health care transition.
Community Supports

Provide youth with special health care needs and their families with connections to our network of Wisconsin collaborators.
Encourage Family Engagement

- Leading by example – leadership support
- Prioritize family engagement activities
- Buy in from families with a thoughtful approach to planning
- Relationships with community partners for local engagement
Unified Approach

- **Alignment** with 6 Core Elements
- **Branding**
- **Common messaging**
Strategies for Engagement

- Wisconsin’s Quality Improvement Grants
- Curricula development
Quality Improvement Grantees

- Family engagement prioritized in grant application
- Identification of youth and family member as part of the local QI team
- Guidance through training
  - Family Voices Wisconsin
  - Center for Patient Partnerships (CPP)
## Family Engagement – Categories

### Categories of Patient Engagement

<table>
<thead>
<tr>
<th>Engagement Categories</th>
<th>Definition and Methods</th>
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<tbody>
<tr>
<td><strong>PARTNER</strong></td>
<td>Patients are full participants&lt;br&gt;Examples: members of a team, governance boards, and improvement initiative work groups.</td>
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<tr>
<td><strong>INVOLVE</strong></td>
<td>Patients are advisors&lt;br&gt;Examples: ongoing Patient Feedback Panels, Patient Advisory Councils, and non-voting participation in patient safety rounds.</td>
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<tr>
<td><strong>DISCUSS</strong></td>
<td>Patients are in dialog with providers and clinic staff&lt;br&gt;Examples: focus group or interviews.</td>
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<tr>
<td><strong>GATHER</strong></td>
<td>Patients are informers.&lt;br&gt;Examples: surveys, cycle time, and suggestion boxes.</td>
</tr>
<tr>
<td><strong>INFORM/Educate</strong></td>
<td>Patients are recipients of information and education&lt;br&gt;Examples: brochures, health information posters, and electronic health records.</td>
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</tbody>
</table>

- ✿ Continuum
- ✿ All valuable
- ✿ Different methods meet different needs
- ✿ Mix and match
- ✿ Consider each stage of QI

Center for Patient Partnerships: www.patientpartnerships.org
Advancing Family Engagement in Health Care Quality Improvement

2017 Children and Youth with Special Health Care Needs Projects Summit

Audiences
Curriculum Development

- Hubs of Expertise
- Core framework – starting with families
- Audience consideration
- Pilot presentations
Multiple Curricula
One Core Framework

- Build Your Bridge
  - Families / Parents
- Bridging the Gap
  - Community / Professional
- Provider Education
  - Clinic settings

www.healthtransitionwi.org
Work Group

Leadership
Advocates
Parents
End Users
Coordinator
CYSHCN staff
Evaluator
Initial Pilot of the Build Your Bridge curriculum took place in Feb – Mar 2017

Presentation Format

• 3 presentations broadcasted on scheduled dates (Adobe Connect or Zoom)

• 2 in-person presentations with time for feedback in focus group style
... and Evaluation

Is it working?

Two types of evaluation:

1. Standard evaluative questions

2. End-user input on content / format
   - Who is the audience?
   - What do they need to know?
   - Is that actually what we’re saying?
Multiple Audiences

Families / Parents

Community / Professional

Providers and Staff (clinic settings)

Youth
Efforts for Outreach

- Quality Improvement (QI) process
- Partnering with key stakeholders
  - 5 Wisconsin Regional Centers
  - QI grantees
  - State partners
  - Grassroots organizations
- Networking
Alignment and Partnerships

Youth Initiatives
- Providers and Teens Communicating for Health (PATCH)
- Adolescent Health Programs (DHS)
- Mental and Behavioral Health Initiatives

Professional Associations
- County Communities on Transition (CCoTs)
- Center for Patient Partnerships

Schools (Educators and Nurses)
- WI Association of School Nurses
What about us?

Photo Credit: PATCH Teen Advocates of WI
Why Adolescent Health?

- Critical and sensitive transition phase
- Developing life long habits
- Majority of adolescents are considered healthy
- Distinct differences in health status and behaviors
  - Unintentional Injuries / Accidents
  - Exploration of sexuality and sexual interactions
  - Mental health and substance abuse
  - Body Image / Obesity

https://healthtransitionwi.org/learningcommunity/
Unique Considerations

- Personal versus professional
- Time, location, transportation
- New to self advocacy, hesitant to speak up
- Multiple priorities
Challenges

- Engagement looks different among audiences
- When is engagement appropriate and at what level
- Constraints (time and budgets)
- Varying levels of priority and availability
- Patience and persistence
Successes

- Partnerships
- Innovative and creative engagement
- Incentives and support
- Transparency (honest but professional)
Commitment to Future Success

- Increase replication and reach
  - Train-the-trainer model
  - Engage more families and health systems in WI
- Increase youth participation
- Positive outcomes for adolescent health care transition
Questions?
Thank You!

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