



Webinar Series: Health Care Transition & Title V Care Coordination Initiatives

A five-part Webinar Series featuring examples of best practices among state Title V agencies, tools and resources, and problem-solving strategies.

Session 5 · Youth, Young Adult & Parent Engagement

- Identifying youth/young adults/parents to participate in HCT initiatives in Title V CC programs
- Providing transition education and training and mentoring opportunities
- Eliciting consumer feedback with HCT care coordination process
- Building youth/young adult/parent leadership roles on HCT within state Title V programs

[Click here to view webinar recording on YouTube](#)

MATERIALS INCLUDE:

- Care Coordination Webinar 5 Slides: Youth, Young Adult & Parent Engagement
- Family Voices Issue Brief: "A Framework for Assessing Family Engagement in Systems Change"
- Progression of Leadership Self-Assessment for Families
- Got Transition Materials
- Wisconsin Transition Materials

Health Care Transition & Title V Care Coordination Initiatives: Webinar Series

Webinar # 5

June 28, 2018

Youth, Young Adult, and Parent Engagement

Peggy McManus, MHS
Co-Director, Got Transition
The National Alliance to Advance Adolescent Health

Mallory Cyr, MPH
Health Care Transition Consultant

Becky Burns, MSSW
Statewide Coordinator
Wisconsin Children and Youth with Special Health Care Needs Program

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



Disclosures and Funding Source

Peggy McManus, Mallory Cyr, Becky Burns, and Maia Stitt have no financial disclosures or conflicts of interest.

Got Transition, a program of The National Alliance to Advance Adolescent Health, is funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, DHHS.



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
- Family Voice's Issue Brief, "A Framework for Assessing Family Engagement in Systems Change" and Eileen Forlenza's "Progression of Leadership Self-Assessment for Families"
- 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

Youth and Family Engagement Levels



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

Baseline Assessment Results

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



Personal Perspective

What does it take to establish authentic and meaningful engagement?

- Time
- Support & training
- Patience
- Flexibility
- \$\$\$
- Buy-in/Leadership



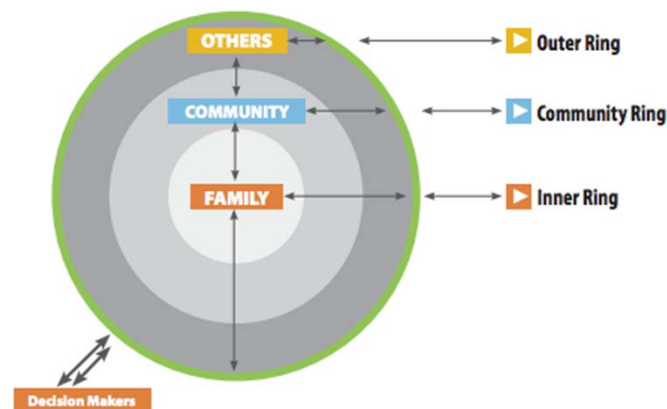
Framing Parent/Family Engagement



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

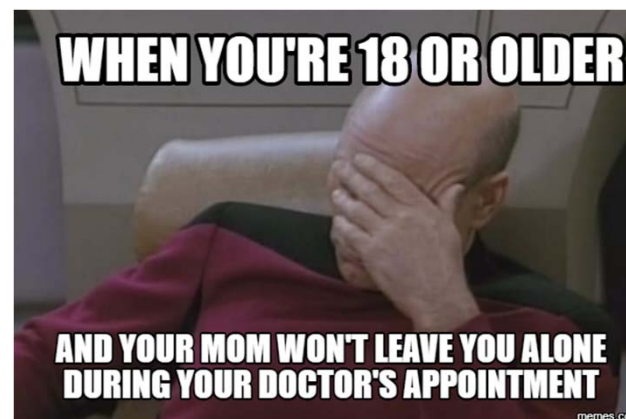
- Asks key questions to help YAs prepare for changes that happen usually between 18 and 22
- Includes tips and linked resources to support YAs to be self-advocates
- LINKS: bit.do/HCTquiz OR gottransition.org/youthfamilies/HCTquiz.cfm

Are You Ready to Transition to
Adult Health Care?



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

Becky Burns, MSSW

Statewide Coordinator

Wisconsin Children and Youth with Special Health Care Needs

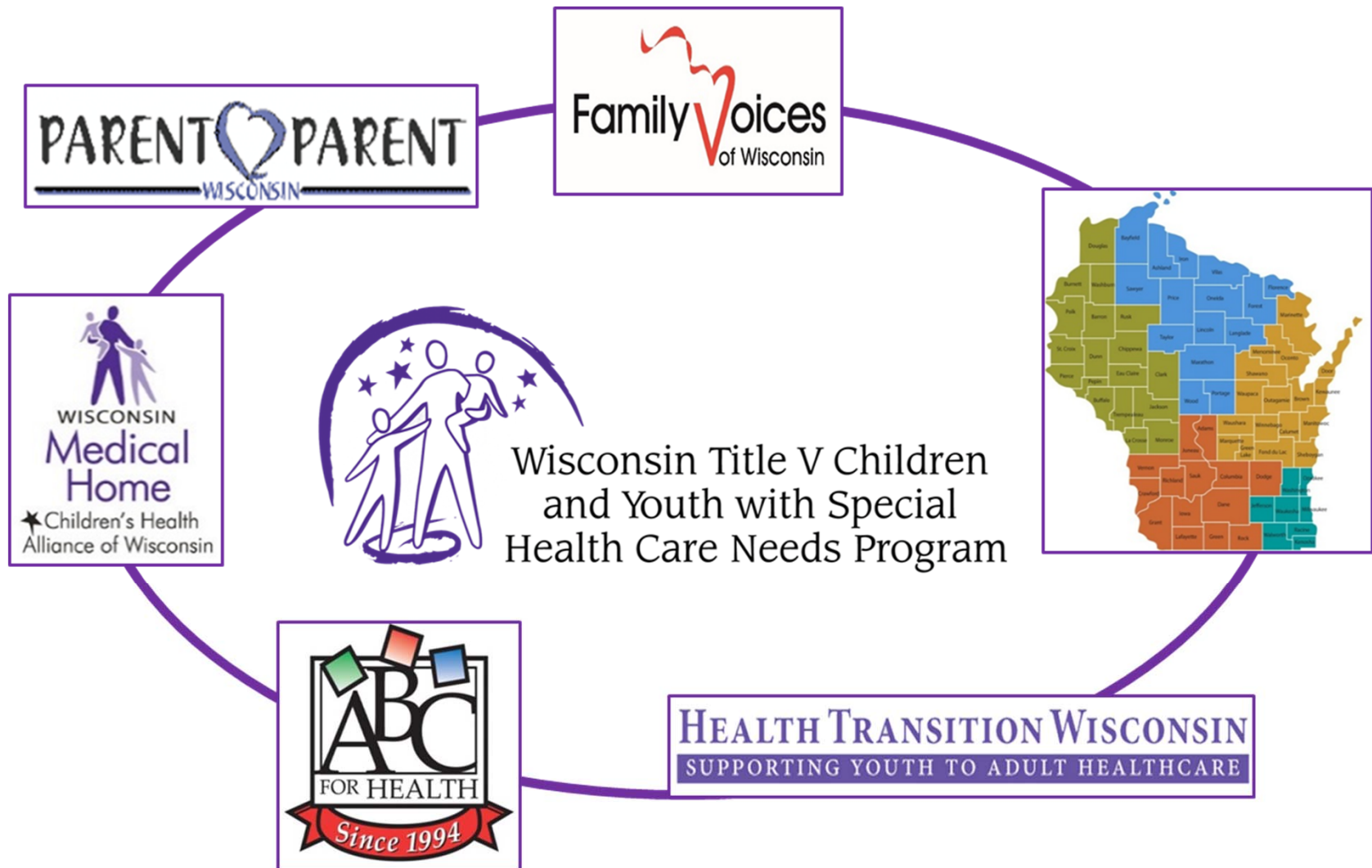
Maia Stitt, MS

Youth Health Transition Initiative Coordinator

Waisman Center



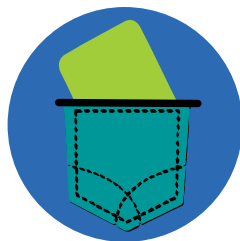
Wisconsin CYSHCN Network



Tools and Resources



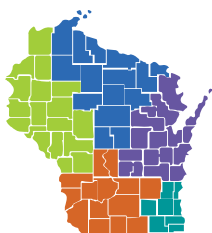
Checklists and
Skill Building



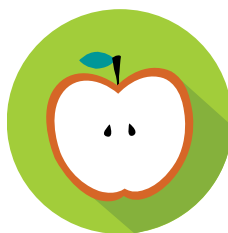
Pocket Guide



Learning
Community



Wisconsin
Regional
Centers



Education and
Awareness
Events



Website



HEALTH TRANSITION WISCONSIN

MOVING FROM CHILD TO ADULT HEALTH CARE



<https://healthtransitionwi.org/>

Youth and Families



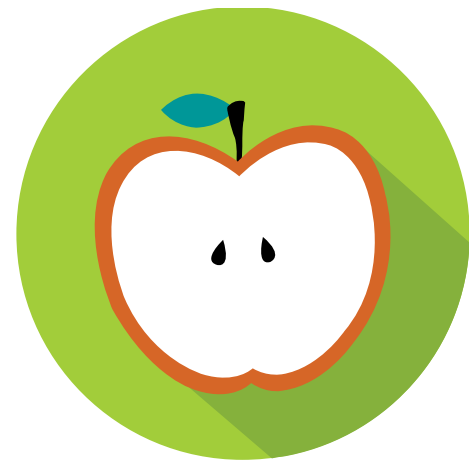
Encourage Wisconsin's youth and their families to make individual choices to enhance their health and well-being.



Provide Wisconsin and national health transition tools and resources.



“Build Your Bridge” trainings.



Health Care Systems



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

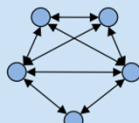
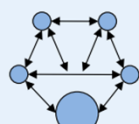
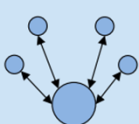
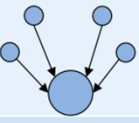
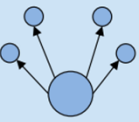


Guidance through training

- Family Voices Wisconsin
- Center for Patient Partnerships (CPP)

Family Engagement – Categories

CATEGORIES OF PATIENT ENGAGEMENT

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

✧ Continuum

✧ All valuable

✧ Different methods meet different needs

✧ Mix and match

✧ Consider each stage of QI

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

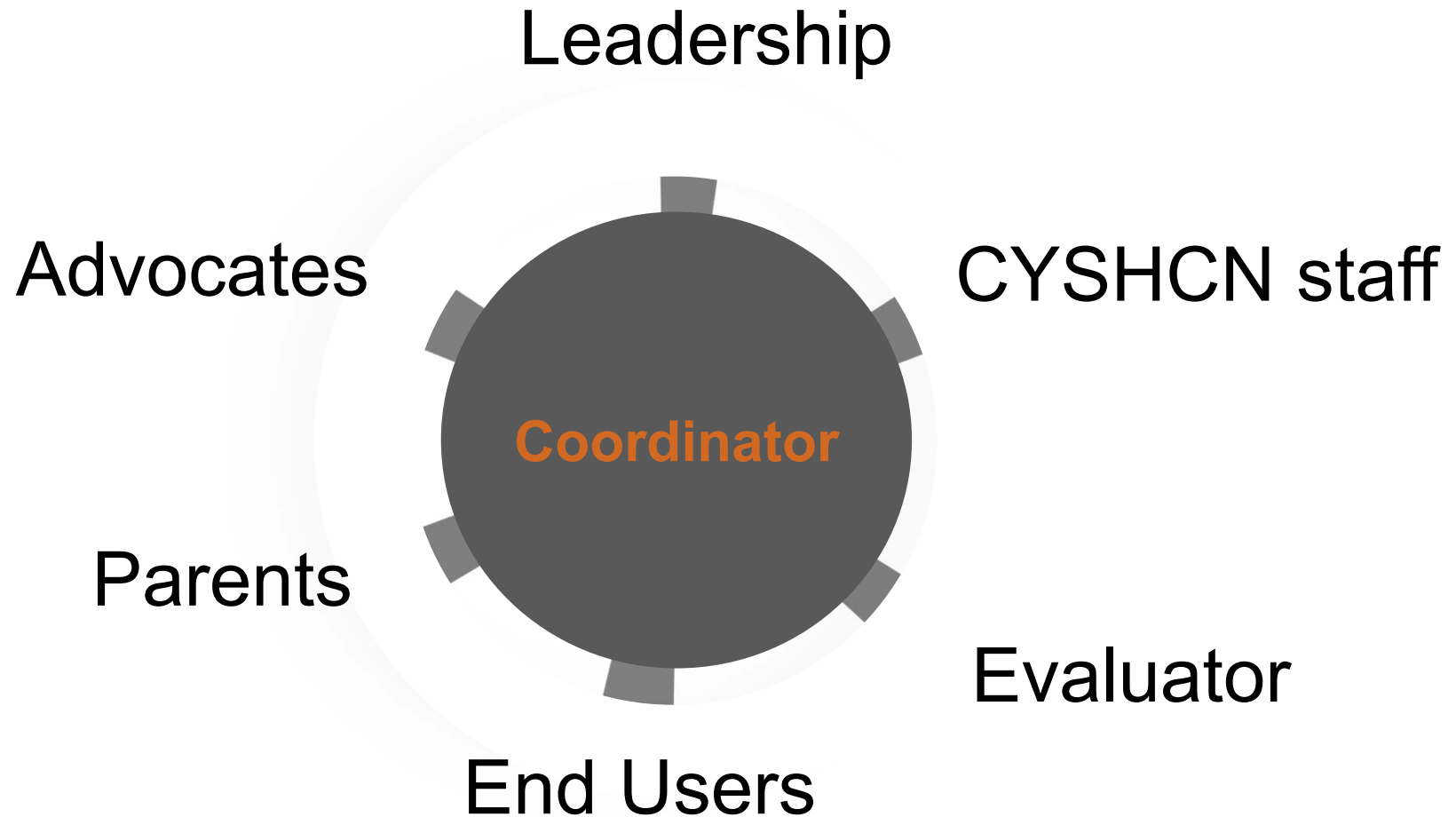
Community / Professional



Provider Education

Clinic settings

Work Group



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



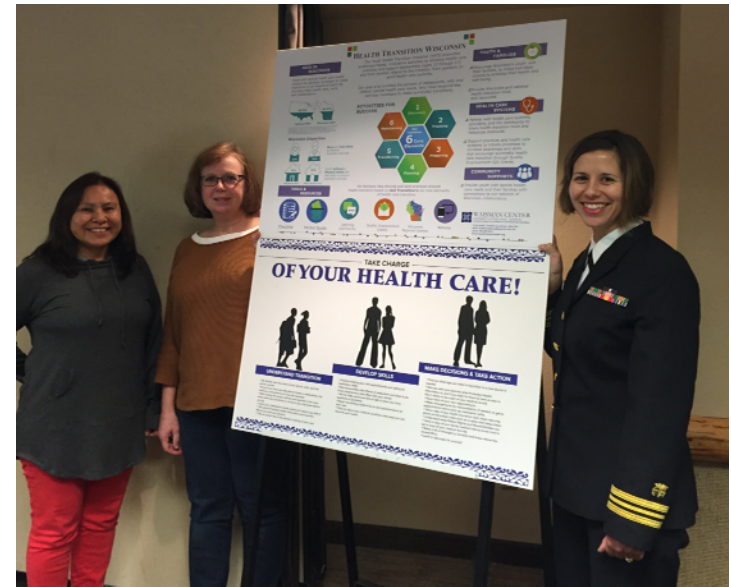
Community / Professional



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

Teen Voices



May 2018 Learning Community

The screenshot shows a Zoom meeting interface. At the top, there is a header bar with the names of participants: Lisa Bennett, Becky Burns, Naomi Kowald, Karen Allsworth, Erica Koepsel, and another person. Below the header, a presentation slide is displayed. The slide has a blue border and contains the following text:

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

At the bottom right of the slide is the PATCH logo, which consists of the word "PATCH" in green and blue letters, with a registered trademark symbol. Below the logo, it says "Providers And Teens Communicating for Health".

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

Title V Care Coordination Webinar Series

**Available for free at Got Transition's
website under Webinars
(www.gottransition.org/webinars)**



Questions?



Thank You!

WEBSITE

www.gottransition.org

EMAIL

mhcyr528@gmail.com

maia.stitt@wisc.edu

rebecca.burns@dhs.wisconsin.gov

mmcmanus@thenationalalliance.org

FACEBOOK PAGE

HealthCareTransition

TWITTER

@gottransition2



Issue Brief

April 2018

A Framework for Assessing Family Engagement in Systems Change

by Clarissa Hoover, MPH, Mary Jo Paladino, MSA, Beth Dworetzky, MS, and Nora Wells, MEd

Abstract

Families of children and youth with special health care needs (CYSHCN) have unique perspectives about the complexities of systems of care because they are involved with so many aspects of these systems. As their children's primary caregivers, families are deeply affected by systems-level issues, such as care fragmentation, which are often a direct result of ineffective or outdated health care policies and practices.¹ Families' lived experiences make them uniquely qualified to partner in shaping systems-level policies that can improve systems of care for all children, especially CYSHCN.^{2,3,4,5,6}

Family Voices is a national, non-profit, family-led organization that works to promote quality health care for all children and youth, particularly those with special health care needs and those from diverse communities. To explore strategies for ensuring, enhancing, and supporting the meaningful engagement of families at the systems level of health care, Family Voices conducted an environmental scan of existing literature and a series of key informant interviews with family leaders and professionals.

This Issue Brief summarizes what we learned from these activities, describing barriers to effective family engagement and identifying four domains and corresponding key criteria that provide a framework for considering how well organizations and agencies are engaging families.

Introduction

In December 2015, the Lucile Packard Foundation for Children's Health hosted a symposium, *Designing Systems That Work for Children with Complex Health Care Needs*,⁷ where families and professionals shared experiences and visions for improving care for CYSHCN.

Discussion topics ranged from care planning and coordination to insurance issues and costs. A key issue was the fragmentation of care for

children served by an array of health care providers and programs that work independently with little communication or coordination. In each session, families and professionals alike recognized that, "working closely with families may be the best way to affect health care outcomes."⁸

Existing evidence shows that family engagement with health care professionals improves care coordination and health outcomes

at the *individual* level – for that child, and that family.⁹ Family Voices recognizes that meaningful family engagement at all levels – including at the *systems* level where existing policies, programs, and services are created or amended – has the potential to be a powerful catalyst for reducing system fragmentation, removing barriers to health care, and improving quality of health care.^{2,3,4,5,6,10} Meaningful engagement of families at this level acknowledges the importance of basing policies, programs, and services on the lived experiences of families who have dealt with this fragmentation and these barriers.¹¹ Family engagement leverages personal knowledge to ultimately improve health systems and outcomes.¹²

Despite the seeming agreement on the value of family involvement, it is still rare for patients to have more than a token amount of power and influence.

Despite the seeming agreement on the value of family involvement, it is still rare for patients to have more than a token amount of power and influence. This work was undertaken to improve understanding of what is needed for effective systems-level family engagement and to begin a process for developing tools that can be used to assess and improve families' meaningful participation.

Findings and Recommendations

This project employed multi-modal engagement activities that are increasingly typical of initiatives based on meaningful family engagement. These activities included:

- Oversight by an expert workgroup of family leaders and professionals.
- A literature review of academic articles and reports.
- Key informant interviews with ten family leaders and nine professionals.
- Review and feedback from the diverse national Family Voices network.

The literature review found qualitative evidence that family engagement at the individual child/provider level resulted in increased satisfaction for both families and health care providers, while noting that family engagement at the systems level has the potential to transform systems of care by improving quality, efficiency, and effectiveness of health care, as well as to result in overall improved health and quality of family life for CYSHCN.¹⁰ However, assessment tools for examining the effectiveness of family engagement are lacking. The literature review also suggested that family engagement was often undertaken without clear goals in mind, perhaps because it was legislatively mandated, encouraged by funders, or required as part of medical home certification.

In the key informant interviews, family leaders and professionals identified barriers to effective family engagement. One key informant noted that, ironically, “The very thing that makes a family member an important player [in systems-level change] – having a child with special health care needs – is often a barrier”¹³ because caring for the child is so time consuming.

Other key informants noted that professionals can be barriers to effective family engagement if they are not receptive to family input and assume they know what is best for families and their children. As one interviewee explained,

when some organizations feel that they are not getting “what they want [from family participants] they start pushing them out and replacing them with people they know.”¹⁴

In one example of family and provider engagement with a payer system, the barrier for both participating families and health care providers was fear. Families were afraid their participation would affect their health care benefits. The health care providers were concerned that their participation would affect their future relationship with the payer.

Other barriers informants noted included failure to provide plain-language materials, meetings held at times that do not accommodate families' schedules, and bringing families in at the end of an initiative, rather than including them from the beginning.

Professional and family leader key informants also identified key criteria that support meaningful family engagement. For example, families and professionals both noted the benefits of training, skill-building opportunities, and mentoring to help family leaders be effective and informed partners and active participants in the family engagement processes.

Definition and Domains of Family Engagement

Integrating definitions of family engagement from the literature with findings from the key informant interviews led to the definition of family engagement as an *authentic partnership between professionals and family leaders who reflect the diversity of the communities they represent, working together at the systems*

level to develop and implement better policies and practices.

Based on a qualitative analysis of the key informant interview responses using NVivo software, the project team identified four domains that are important for promoting and ensuring meaningful and sustainable family engagement at the systems level. The four domains – representation, transparency, impact, and commitment – are explained in detail below. For each domain, the project proposed key criteria to help organizations support and enhance family engagement activities at the systems level. Organizations can use these criteria as an initial checklist or rephrase the criteria as questions to use as a self-assessment.

Four Domains of Family Engagement in Systems

Representation

- Reflect the diversity of the community (race, ethnicity, language, income, education level, and geography)
- Partner with family-led and community-based organizations

Transparency

- Provide access to relevant knowledge
- Practice partnership in all parts of the process

Impact

- Identify what has changed and what the organization or system of care is doing differently because families were involved

Commitment

- Promote engagement as a core value
- Establish engagement at all levels, in all systems of care

Representation

Representation is the process by which family leaders stand in for the rest of their community in systems-level activities such as needs assessment and strategic planning. Family leader representation should reflect the diversity of the community served by the agency in which the families are involved.

Does your organization partner with a family-led organization to help identify, support, and mentor family participation?

Family leaders come from many different backgrounds and some may not be comfortable with professional skills – such as effective participation in meetings, constructive communication, making presentations, and understanding data – that are routine in the work environments of health professionals. Family-led organizations are key partners to ensure prepared, representative family-leaders in systems level participation.

Key criteria that help lead to successful representation:

- Collaborate with family-led and community-based organizations for recruitment, training, and support of participants. Building relationships with organizations that regularly provide information, referral and peer support to families, such as Family Voices State Affiliate Organizations and Family-to-Family Health Information Centers, can help professional groups create a sustainable approach to engaging families at the systems level. These family-led organizations also can provide training and mentoring for families and professionals around effective, sustained relationships.
- Provide peer mentors to help family leaders learn the skills to participate effectively and address barriers to their participation. Do not expect family leaders to do something alone if they have not done it before, or if they are uncomfortable with a task. Having a mentor at their side is particularly important in activities that may be emotionally, as well as logistically, challenging, such as attending a professional conference for the first time.
- Ensure that family participants represent the race, ethnicity, language, income, education level, and geography of those who receive the services provided by the organization. Identify priority communities and stakeholders to be part of the family engagement process. Community-based organizations often serve specific populations of families and can provide cultural brokers to help recruit and support families to participate.
- Create a friendly, supportive environment that welcomes the contributions each participant brings to the process.
- Hold meetings that accommodate everyone's schedules to encourage regular attendance. In-person meetings facilitate relationship building between families and professionals.
- Compensate family organizations and family leaders for their time, expertise and the costs of participation, such as travel expenses and childcare.

- Provide special accommodations, including arrangements for access and comfort for participants with physical disabilities, and materials in multiple languages.

Transparency

Transparency assures access to the knowledge that allows all partners to fully participate in the process, and maximize their own effectiveness.

Does your organization provide the supports and information that both families and professionals need to be informed participants in systems-level change?

Families and professionals benefit from developing or enhancing key practices to support transparency and the associated values of openness and inclusion. Partnering with family-led organizations is critical to transparency.

Key criteria that help ensure transparency:

- Family leaders partner in all parts of the process, from brainstorming to evaluation.
- Committees, boards, and other groups with defined structures have at least two positions reserved for family leaders.
- People with dual roles (family of a CYSHCN who is also a professional or family member hired as a representative within an organization) may make a unique contribution, using their experience with both perspectives to foster better communication and to identify barriers. However, they also may find themselves in a position of conflict of interest. These dual-role

individuals should not take the place of family leaders from outside the organization who represent the broader patient community.

- Acronyms are spelled out and their meaning explained. Use plain language when writing and speaking.
- If family leaders are excluded from important activities, professionals champion family perspectives and work towards greater inclusion of family leaders.
- Meeting minutes and other key materials are available to family leaders, in formats they can access, in language they can understand, and in a timely way.
- Confidentiality requirements are carefully explained.
- Families and professionals both have opportunities for training and support in understanding their roles and the process of engagement. All participants are helped to recognize their own cultural context and biases.
- Professional partners work to understand the strengths of family leaders and of the community at large, and design activities to take advantage of those strengths.

Impact

Impact describes what the organization is doing differently because it has engaged families in creating systems-level change.

What is your organization doing differently because of engaging families at the systems level? Family engagement succeeds when organizations work with family partners to learn from their experiences, and when they

implement changes to improve policies that reduce barriers to health care or resolve other systems-level issues. These successes provide the foundation for sustained family engagement because family leaders are willing to commit more time and energy when they know that they are making a difference. Successful family participation also can result in increased commitment from professionals to cultivate family engagement.¹⁰

Key criteria that help ensure the impact of family engagement at the systems level:

- Family leaders' input is valued, acknowledged, and helps lead to change.
- Family leaders influence decisions about existing policies and programs and help select and prioritize new issues to address.
- Family leaders are able to influence the process for how decisions are made in policies and programs.
- Professional partners and family leaders can explain how family leaders contributed to improved outcomes or processes.
- Family leaders, family organizations and professionals partner in evaluation and improvement of family engagement activities.

Commitment

Commitment means that family engagement is normalized and included throughout the activities that impact the organization at the systems level.

Does your organization educate and inform all staff about the importance of engaging

families at the systems level, valuing families' time, and respecting their contributions?

Professionals and family leaders need to celebrate and publicize successes and speak out when they see missed opportunities for family engagement.

Key criteria that demonstrate an organization's commitment to family engagement:

- Family engagement is embedded as a core value in the culture of the organization, expressed in written policies, and does not change with changing leadership.
- Family engagement is mandated by those who have the authority to do so, including funders, payers, management, and policymakers.
- Family engagement is adequately funded; costs of a family engagement plan are included in the budget.
- Agency budgets ensure adequate staff time for implementing any changes made because of family engagement. This may include time for educating health care providers and other staff about different or new policies and practices.
- Journal articles, reports, and other publications are jointly authored with family partners, and describe the family-engagement activities that supported the work.
- Opportunities to become family leaders who influence outcomes at the systems level through engagement activities are available and accessible to a wide range of families and caregivers, supported by family-led organizations.

Conclusions

Health care providers, payers, and systems of care increasingly focus on meaningful family engagement as a strategy to improve health care systems, enhance consumer and provider satisfaction, and reduce costs. This Issue Brief describes four domains that can contribute to

family engagement in systems-level change and lists key criteria organizations can use to assess how well they are engaging families. Analyzing the use of these criteria will help build an evidence base for how family engagement contributes to improving systems of care and health outcomes for CYSHCN and other populations.

References

1. Institute of Medicine (US); Stoto MA, Behrens R, Rosemont C, editors. Healthy People 2000: Citizens Chart the Course. Washington (DC): National Academies Press (US); 1990. 7., People with Disabilities. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK235783/>
2. Funchess, M, Spencer, S, & Niarhos, M. (2014). The Evolution: Family-Driven Care as a Practice. National Federation of Families for Children's Mental Health: Rockville, MD.
3. Howrey, BT, Thompson, BL, Borkan, J, Kennedy, LB, Hughes, LS, Johnson, BH, ... & Degruy, F. (2015). Partnering with patients, families, and communities. *Fam Med*, 47(8), 604-11.
4. Health Research & Educational Trust. (2015). Partnering to improve quality and safety: A framework for working with patient and family advisors. Chicago, IL: Health Research & Educational Trust. Accessed at www.hpoe.org on January 30, 2017.
5. Kuhlthau, KA, Bloom, S, Van Cleave, J, Knapp, AA, Romm, D, Klatka, K, ... & Perrin, JM. (2011). Evidence for family-centered care for children with special healthcare needs: a systematic review. *Academic pediatrics*, 11(2), 136-143.
6. Reynolds, MC, Birzer, M, St John, J, Wells, N, Anderson, B, & Walker, DK. (2015). Family Leaders and Workforce Leadership Development. *Maternal and child health journal*, 19(2), 252.
7. <https://www.lpfch.org/publication/proceedings-2015-symposium-designing-systems-work-children-complex-health-care-needs>
8. Olson, S. (2015). Proceedings for the 2015 Symposium: Designing Systems That Work for Children with Complex Health Care Needs. Palo Alto, CA: The Lucile Packard Foundation for Children's Health.
9. Cené, CW, Johnson, BH, Wells, N, Baker, B, Davis, R, and Turchi, R. (2016). A Narrative Review of Patient and Family Engagement: The "Foundation" of the Medical "Home". *Med. Care*, 54(7):697-705.
10. Hoover, C, Agoratus L, Vickers, M, Richey A, Walker, DK, and Wells, N. (2018) Family Engagement in Systems: Literature Review. Albuquerque, NM: Family Voices.
11. Committee on the Learning Health Care System in America; Institute of Medicine; Smith M, Saunders R, Stuckhardt L, et al., editors. Best Care at Lower Cost: The Path to Continuously Learning Health Care in America. Washington (DC): National Academies Press (US); 2013 May

10. 7, Engaging Patients, Families, and Communities. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK207234/>.
12. Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223-231.
13. Shared by a family leader key informant for this project.
14. Shared by a professional key informant for this project.

Acknowledgements

Family Voices is grateful for the guidance, recommendations, input, and time that our Expert Workgroup members provided to ensure the success of this project.

Lauren Agoratus, MA, Coordinator, Statewide Parent Advocacy Network of New Jersey (SPAN).

Joni Bruce, Executive Director, Oklahoma Family Network

Juno Duenas, Executive Director, Support for Families

Merrill Friedman, Vice President of Advocacy, Amerigroup, Wellpoint, Inc., VA.

Donna Johnson, Title V CYSHCN Director, GA.

Carolyn S. Langer, MD, MPH, JD, Chief Medical Officer, MassHealth, MA; Director, Office of Clinical Affairs.

Julie Lucero, Ph.D., MPH, Assistant Professor, University of Nevada, Reno.

Lisa Rossignol, MA, Healthcare Liaison, Parents Reaching Out (PRO), NM.

Yolanda Sandoval-Nez, Native American Disability Law Center, NM

Renee Turchi, MD, Assistant Professor, Drexel University, PA.

Deborah Klein Walker, EdD, Adjunct Professor, Boston University School of Public Health

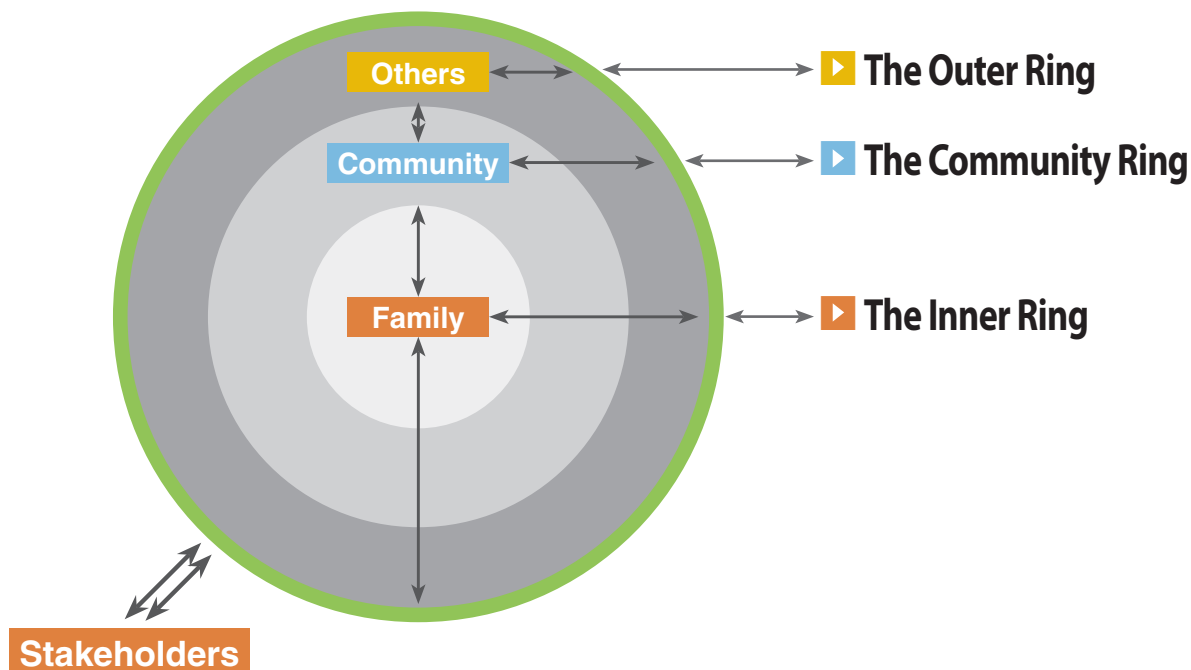
Additional thanks to Dr. Julie Lucero and Kathrine Wright, both of the University of Nevada, Reno, for their expert work coding the key informant interviews.

ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health is a public charity, founded in 1997. Its mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families.

The Foundation encourages dissemination of its publications. A complete list of publications is available at <http://www.lpfch.org/publications>

CONTACT: The Lucile Packard Foundation for Children's Health, 400 Hamilton Avenue, Suite 340, Palo Alto, CA 94301
cshcn@lpfch.org (650) 497-8365

Self-Assessment Progression of Leadership



Where do you think you are in the progression of family leadership?

Explain: _____

How interested are you in going to the next level?

Not At All ← 1 — 2 — 3 — 4 — 5 → Very Interested

For you to progress to the next level, what supports do you need? _____

What are some activities that you would like to do as a result of developing your leadership skills?

Explain: _____

Examples of...

▶ **The Inner Ring** (*Family*):

1. Attend classes on Parenting skills or Child Development.
2. Attend a training to feel confident about your child's Care Plan or IEP.
3. Follow through on referrals to specialists .
4. Learn how to effectively coordinate your child's health care needs.
5. Have a list of local support groups in the area.
6. Keep good records of your child's health care visits.
7. Keep a list of my child's providers – including physician, therapist, pharmacy.

▶ **The Community Ring**:

1. Plan and implement a community forum or training.
2. Work with local partners to sponsor a family to attend community meetings or trainings.
3. Develop a local support group and work with a community partner to donate their space for the meeting.
4. Write an article about a family success story and ask agencies to include it in their newsletter.
5. Partner with your provider to develop a satisfaction survey for families.
6. Develop a list of local support groups and share it in the community (library, grocery store, waiting rooms, etc.).
7. Create a forum to hear from families regarding their overall wellness needs – some of which may include other “systems” (foster care, autism meetings, grief support, etc.).

▶ **The Outer Ring** (*Others*):

1. Attend professional development trainings to support your skills as a Family Leader.
2. Work with a hospital or school district to review aggregate data of family satisfaction surveys.
3. Recommend policy changes as a result of surveys/ assessments.
4. Participate in grant writing to assure the perspective of families is integrated in program development.
5. Participate as a content expert on a Quality Improvement team.
6. Establish yourself as a consultant and professionally offer consultative reports including policy recommendations.
7. Be informed about legislative issues that will impact children and families.
8. Prepare and deliver an impactful legislative testimony.
9. Develop and lead an advisory council at the hospital, school district or state agency.

FOR YOUTH & YOUNG ADULTS:

QUESTIONS TO ASK YOUR DOCTOR ABOUT TRANSITIONING TO ADULT HEALTH CARE

DURING YOUR ADOLESCENT YEARS:

- ☐ When do I start to meet with you on my own for part of the visit to become more independent when it comes to my own health and health care?
- ☐ What do I need to learn to get ready for adult health care? Do you have a checklist of self-care skills that I need to learn?
- ☐ Can I work with you to prepare a Medical Summary and Emergency Care Plan?
- ☐ When I turn 18, what information about privacy and consent do I need to know about? If I need help with making health decisions, where can I get information about this?
- ☐ At what age do I need to change to a new doctor for adult health care?
- ☐ Do you have any suggestions of adult doctors to transfer to?

BEFORE MAKING THE FIRST APPOINTMENT TO A NEW ADULT DOCTOR:

- ☐ Do you take my health insurance?
- ☐ Where is your office located? Is there parking or is it near a metro/bus stop?
- ☐ What are your office hours, and do you have walk-in times?
- ☐ What is your policy about making and cancelling appointments?
- ☐ If needed, can the new adult doctor help me find adult specialty doctors?

BEFORE THE FIRST VISIT TO THE NEW ADULT DOCTOR:

- ☐ Did you receive my medical summary from my pediatric doctor? (Call your pediatric doctor to remind them to send the medical summary before your first visit to the new adult doctor.)
- ☐ What should I bring to the first visit?



Please visit www.gottransition.org
for more information.



FOR PARENTS:

QUESTIONS TO ASK YOUR CHILD'S DOCTOR ABOUT TRANSITIONING TO ADULT HEALTH CARE

DURING YOUR CHILD'S ADOLESCENT YEARS:

- ☐ When does my child start to meet with you on their own for part of the visit to become more independent when it comes to their own health and health care?
- ☐ What does my child need to learn to get ready for adult health care? Do you have a checklist of self-care skills that my child needs to learn?
- ☐ Can I work with you to prepare a Medical Summary and Emergency Care Plan for my child?
- ☐ Before my child turns 18 and becomes a legal adult, what information about privacy and consent do we need to learn about? If my child needs help with making health decisions, where can I get information about this?
- ☐ At what age does my child need to change to a new doctor for adult health care?
- ☐ Do you have any suggestions of adult doctors for my child to transfer to?

BEFORE MAKING THE FIRST APPOINTMENT TO A NEW ADULT DOCTOR:

- ☐ Do you take my health insurance?
- ☐ Where is your office located? Is there parking or is it near a metro/bus stop?
- ☐ What are your office hours, and do you have walk-in times?
- ☐ What is your policy about making and cancelling appointments?
- ☐ If needed, can the new adult doctor help find adult specialty doctors?

BEFORE THE FIRST VISIT TO THE NEW ADULT DOCTOR:

- ☐ Did you receive my medical summary from the pediatric doctor? (If not, call the pediatric doctor to remind them to send the medical summary before your first visit to the new adult doctor.)
- ☐ What should I bring to the first visit?



Please visit www.gottransition.org
for more information.





Sample Health Care Transition Feedback Survey for Youth

Six Core Elements of Health Care Transition 2.0

This is a survey about your experience changing from pediatric to adult health care. You may choose to answer this survey or not. Your responses to this survey are confidential.

1. How often did your previous health care provider explain things in a way that was easy to understand?
☐ Always
☐ Usually
☐ Sometimes
☐ Never
2. How often did your previous health care provider listen carefully to you?
☐ Always
☐ Usually
☐ Sometimes
☐ Never
3. Did your previous health care provider respect how your customs or beliefs affect your care?
☐ A lot
☐ Some
☐ A little
☐ Not at all
4. Did your previous health care provider discuss with you or have an office policy that informed you at what age you may need to change to a new provider who treats mostly adults?
☐ Yes
☐ No
5. Did you talk with your previous health care provider without your parent or guardian in the room?
☐ Yes
☐ No
6. Did your previous health care provider actively work with you to gain skills to manage your own health and health care (e.g., know your medications and their side effects, know what to do in an emergency)?*
☐ A lot
☐ Some
☐ A little
☐ Not at all
7. Did your previous health care provider actively work with you to think about and plan for the future (e.g., take time to discuss future plans about education, work, relationships, and development of independent living skills)?*
☐ A lot
☐ Some
☐ A little
☐ Not at all
8. How often did you schedule your own appointments with your previous health care provider?
☐ Never
☐ Sometimes
☐ Usually
☐ Always
9. Did your previous health care provider explain legal changes in privacy, decision-making, and consent that take place at age 18?
☐ Yes
☐ No
10. Did your previous health care provider actively work with you to create a written plan to meet your health goals and needs?*
☐ Yes
☐ No
11. Did your previous health care provider create and share with you your medical summary?
☐ Yes
☐ No
12. Did your previous health care provider have information about community resources?
☐ Yes
☐ No
13. Do you know how you will be insured as you become an adult?*
☐ Yes
☐ No

Continued »



Sample Health Care Transition Feedback Survey for Youth

Six Core Elements of Health Care Transition 2.0

14. Did your previous health care provider assist you in identifying a new adult provider to transfer to?

- ☐ Yes
☐ No

15. Did your adult health care provider have your medical records before your first visit?

- ☐ Yes
☐ No
☐ Don't Know
☐ Have not had first visit yet

16. Did you feel prepared to change to an adult health care provider?

- ☐ Very prepared
☐ Somewhat prepared
☐ Not prepared

17. At what age did you change to an adult health care provider?

Age _____

18. How could your pediatric health care provider have made your move to an adult health care provider better?

Thank you.

*Adapted from the National Survey of Children's Health



Sample Health Care Transition Feedback Survey for Parents/Caregivers

Six Core Elements of Health Care Transition 2.0

This is an optional survey about your experience changing from pediatric to adult health care. If you choose to, please answer each question by marking the box to the left of the answer. Your responses to this survey are confidential.

1. How often did your child's health care provider explain things in a way that was easy to understand?
☐ Always
☐ Usually
☐ Sometimes
☐ Never
2. How often did your child's health care provider listen carefully to you?
☐ Always
☐ Usually
☐ Sometimes
☐ Never
3. Did your child's health care provider respect how your customs or beliefs affect your care?
☐ A lot
☐ Some
☐ A little
☐ Not at all
4. Did your child's health care provider discuss with you or have an office policy that informed you at what age your child may need to change to a new provider who treats mostly adults?
☐ Yes
☐ No
5. Did your child talk with your health care provider alone while you waited in the waiting room?
☐ Yes
☐ No
☐ Not applicable (if child has significant intellectual disabilities)
6. Did your child's health care provider actively work with your child to gain skills to manage his/her own health and health care (e.g., know his/her medications and their side effects, know what to do in an emergency)?*
☐ A lot
☐ Some
☐ A little
☐ Not at all
7. Did your child's health care provider actively work with your child to think about and plan for the future (e.g., take time to discuss future plans about education, work, relationships, and development of independent living skills)?*
☐ A lot
☐ Some
☐ A little
☐ Not at all
8. How often did your child schedule his/her own appointments with his/her previous health care provider?
☐ Never
☐ Sometimes
☐ Usually
☐ Always
☐ Not applicable
9. Did your child's health care provider explain legal changes in privacy, decision-making, and consent that take place at age 18?
☐ Yes
☐ No
10. Did your child's health care provider actively work with your child and you to create a written plan to meet his/her health goals and needs?*
☐ Yes
☐ No
11. Did your child's health care provider create and share his/her medical summary with your child and you?
☐ Yes
☐ No
12. Did your child's health care provider have information about community resources?
☐ Yes
☐ No

Continued »



Sample Health Care Transition Feedback Survey for Parents/Caregivers

Six Core Elements of Health Care Transition 2.0

13. Do you know how your child will be insured as he/she becomes an adult?*

☐ Yes

☐ No

14. Did your child's health care provider assist in identifying a new adult provider to transfer to?

☐ Yes

☐ No

15. Did your child's adult health care provider have his/her medical records before the first visit?

☐ Yes

☐ No

☐ Don't Know

☐ Have not had first visit yet

16. Did your child feel prepared to change to an adult health care provider?

☐ Very prepared

☐ Somewhat prepared

☐ Not prepared

☐ Not applicable

17. At what age did your child change to an adult health care provider?

Age _____

18. How could your child's health care provider have made the move to an adult health care provider better for you and your child?

Thank you.

*Adapted from the National Survey of Children's Health

Presentation Links - June 2018

Wisconsin Youth Health Transition Initiative

Slide 1 Wisconsin Youth Health Transition Initiative

The Wisconsin Youth Health Transition Initiative is focused on providing up-to-date health care transition resources, materials, events and news related to health care transition for adolescent aged youth. This includes information and resources to drive individual, family, clinic practices, an organization's transition initiatives forward, offering statewide activities such as webinars and conferences taking place in Wisconsin and nationally.
www.healthtransitionwi.org

Slide 1 Wisconsin Medical Home Initiative (website)

Physicians can learn strategies for promoting family involvement in clinic practice, and trainings are available for families on how to partner with their child's physician. Conversations are focused on how families and physicians can share decision-making to promote optimal outcomes for children.
www.wismhi.org/wismhi/Clinicians/Family-Partnership

Slide 1 Family Voices of Wisconsin (website)

Helps families who have children with disabilities or special health care needs navigate health care and community supports. Their work focuses on education and information, family leadership and policy and systems change. They are the home of the Family Voices state affiliate organization and Wisconsin's Family to Family Health Information Center. In addition, they are recognized as the family leadership hub for Wisconsin's Children and Youth with Special Health Care Needs partnership.
www.familyvoicesofwisconsin.com

Slide 9 Center for Patient Partnerships (website)

The Center for Patient Partnerships works to empower patients in the healthcare system, advocating for patients and their families, educating future professionals, and performing research to help make medicine more inclusive.
www.patientpartnerships.org

Slide 9 Patient Engagement in Redesigning Care (toolkit resources)

Intended for use by hospital and clinic directors, managers, clinicians and researchers, this resource contains tools to strengthen the role of patients in teams designing health care delivery and quality improvements
<https://www.hipxchange.org/PatientEngagement>

Slide 10 Family Engagement Categories (pdf)

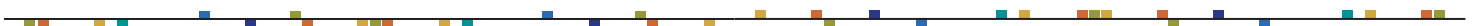
Intended for use in family engagement. Link to figure referenced in presentation.
www.wismhi.org/-wismhi-files/PDF/Clinicians-tab/PT.engagement.categories.pdf

Slide 19 Providers and Teens Communicating for Health (PATCH) (website)

They work in our communities to educate, engage, and empower young people in the State of Wisconsin to take control of their own health.
www.wipatch.org

Slide 21 Learning Community May 2018 (direct link to presentation)

Successfully Partnering with Youth: Strategies for Including Young Adult Perspectives to Improve Adolescent Health Outcomes – Wisconsin Transition Learning Community & PATCH
Presenters: Erica R. Koepsel, MA PATCH Program Manager and Eliette Soler, PATCH Teen Educator
View presentation at the following link: <https://www.youtube.com/watch?v=p6wuJdHpl-E>



HEALTH TRANSITION WISCONSIN

MOVING FROM CHILD TO ADULT HEALTH CARE

NATIONAL & STATE PERFORMANCE

Very few youth receive the services necessary to successfully transition to adult life. These include areas like adult health care, decision-making, work, and independence.

Nationwide



Wisconsin



The Wisconsin Youth Health Transition Initiative helps youth (ages 12 through 17), their families, and their health care team prepare for the change from child to adult health care.

We offer information, tools, and resources about what to expect and how to prepare.

Our goal is to increase the number of youth who receive the support necessary to feel confident making individual choices about their health and health care.

We encourage idea sharing and best practices around health transition based on **Got Transition's Six Core Elements** of health care transition.



YOUTH & 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

HEALTH CARE SYSTEMS



- 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.

TOOLS & RESOURCES AVAILABLE



Checklists & Skill Building



Pocket Guide



Learning Community



Wisconsin Regional Centers



Education & Awareness Events



Website



WAISMAN CENTER

UNIVERSITY OF WISCONSIN - MADISON
University Center for Excellence in Developmental Disabilities

Youth Health Transition Coordinator: **Maia Stitt**
email: healthtransitionwi@waisman.wisc.edu
phone: 608.265.9423

healthtransitionwi.org

Annotated Transition Resources

Wisconsin Youth Health Transition Initiative

Insights into the Patient and Family Experience

1. Betz, C.L., Lobo, M.L., Nehring, W.M., & Bui, K. (2013). Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook*, 61, 311-336.
<http://dx.doi.org/10.1016/j.outlook.2013.01.008>

Thirty-five studies met the criteria for this systematic review of literature concerning the health care transition needs of adolescents and emerging adults with special health care needs. Findings indicated that these individuals want to be part of the transition process and seek providers who will listen and appropriately support their unique care needs. Some of the challenges for patients include a lack of a) organized transfer processes from pediatric to adult care, b) anticipatory guidance about health care transitions and, c) understanding of the differences between pediatric and adult care delivery systems. More research is needed to guide evidence-based practice.

2. Geenen, S.J., Powers, L.E., & Sells, W. (2003). Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Journal of Adolescent Health*, 32(3), 225-233. [An older article yet offers relevant insights]

Two parallel surveys, one of parents of adolescents with special health care needs and the other of health care providers (mostly pediatricians), demonstrated significant differences in the respective perceptions about the involvement and extent of providers' responsibility across 13 transition activities. Broadly, parents were more focused on access, quality, and coordination of care while providers focused on health promotion (e.g., discussion on drugs, alcohol, sexual issues, and general health management). Despite several study limitations, the findings suggest a need for providers, adolescents, and their parents to openly discuss care needs and priorities relevant to transition activities.

3. Hopper, A., Dokken, D., & Ahman, E. (2014). Transitioning from pediatric to adult health care: The experience of patients and families. *Pediatric Nursing*, 40(5), 249-252.

This article includes personal perspectives from three young adults with complex health needs. Challenges and strategies relevant to meeting their needs are discussed and provide insights for improving the health transition experience for patients and providers alike.

4. O'Sullivan-Oliveira, J., Fernandes, S.M., Borges, L.F., & Fishman, L. N. (2014). Transition of pediatric patients to adult care: An analysis of provider perceptions across discipline and role. *Pediatric Nursing*, 40(3), 113-120 & 142.

Across four provider focus groups, 28 providers (primary and specialty care; physicians, physician assistants, nurse practitioners, registered nurses, and social workers) participated in semi-structured interviews concerning their perceptions about transition care and their patients' self-care management. Six themes emerged: 1) identifying the appropriate time or age for transition, 2) providers' challenge to support and encourage transition (i.e., reluctance to let go), 3) parental and patient fears related to transitioning to a new provider (i.e., fear of the unknown; lessening of parental involvement), 4) lack of provider experience and comfort with meeting transition needs, 5) need for consistent transition policies and tools, and 6) need for a collaborative pediatric/adult team approach to transition.





Insights into the Patient and Family Experience *(continued)*

5. WITH Foundation (formerly The Special Hope Foundation). (2016). Bridging the gap: Improving healthcare access for people with disability. Available at <https://withfoundation.org/>

Though specifically directed to health care professionals, this video is a powerful teaching tool for anyone seeking to understand how to best support people with disabilities. A woman with a disability and her husband share their experiences -- both good and bad -- with health care professionals. Their perspectives offer valuable teaching points for health care providers.

Total time: 10.43". Alternate shorter version (6.09"):

<https://drive.google.com/file/d/0B5PGH8Hjq-zsZThBQkIJRE1kSzA/view?pref=2&pli=1>

6. WITH Foundation (formerly The Special Hope Foundation). (2016). Supported decision making Gabby's story. Available at <http://specialhope.org/>

This video, useful for anyone supporting individuals with disabilities, focuses on the topic of supported decision-making from the perspective of a young woman with spina bifida. She shares her very personal feelings -- being scared of making a decision to have eye surgery and shutting down; feeling great to have support in making decisions, and having others see her as she would like to be seen.

There is an assumption that a person with a disability is a perpetual child. Guardianship in appointing someone else to make decisions can take away the legal status of an individual and make it a legal reality. Most people with disabilities are able to make their own choices yet some like others to help them make decisions. Individuals in this video also advocate for a legally recognized model of supported decision-making.

Total time: 10.56". Alternate shorter version (9.29"): <http://specialhope.org/healthcare-access-for-people-with-disabilities-special-hopes-video-shorts-tell-the-story/>

Wisconsin-Specific Health Care Provider and Patient Resources

1. Wisconsin Department of Health Services. (2016). Aging and Disability Resource Centers (ADRC) Consumer Page. Available at <https://www.dhs.wisconsin.gov/adrc/index.htm>

Each of Wisconsin's 72 counties has an Aging and Disability Resource Center. These are intended as "one-stop" sites for information and assistance regarding services available for all individuals 18 years of age and older living in Wisconsin. Adult health care providers may refer a patient to the patient's respective ADRC (based on county of residence) for general information on community resources available or for options counseling if the patient is in need of services to support management of chronic conditions or other special health care needs.

2. Wisconsin Department of Health Services. (2016). Regional centers for children and youth with special health care needs (CYSHCN). Available at <https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm>

Five Regional Centers dedicated to supporting families with children and youth with special health care needs and the providers who serve them; special focus on youth transition. Locations: Chippewa Falls (Western), Madison (Southern), Neenah (Northeast), Wausau (Northern), and Wauwatosa (Southeast).