Greetings from the Adolescent and Young Adult Health National Resource Center (AYAH Center)!

Your friends and colleagues are pleased to be sharing our bi-monthly newsletters with you. Throughout the year, we will use this newsletter to:

- Provide information about trending topics in adolescent and young adult health and health care
- Share our resources, including resources from the Collaborative Improvement and Innovation Network (CoIIN)
- Keep you up-to-date about upcoming events related to adolescent and young adult health and health care

To subscribe to the newsletter, email Kristen Taylor at ktaylor@amchp.org. We welcome your ideas and feedback, and you are free to unsubscribe at any time.

How are Parents Engaged in Adolescent’s Health Care?
Implications from new research

An Interview with Judy Klein, President of Unity Consortium

Can you briefly describe Unity Consortium and its research?
The Unity Consortium is an action-oriented, nonprofit organization with diverse members and a common objective – to improve adolescent and young adult health through a focus on prevention and immunization. Unity recently conducted a teen health survey via Harris poll, which revealed major areas for improvement in preventive health communications to teens and their parents. For example, the survey revealed that four in ten parents (41 percent) believe their teen should only see a doctor when he/she feels sick and that more than one-third of teens (34 percent) don’t know how being vaccinated helps them.

What were you hoping to learn about parents and preventive health care for adolescents?
We wanted to get a better understanding of parents’ beliefs and practices regarding preventive health care for teens and how their beliefs compare to those of health care providers and teens themselves. Not surprisingly, we found that beliefs don’t always translate into action. For instance, a clear majority of parents believe it is
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**What were the highlights of what you learned?**

One of our key learnings was that teens are genuinely interested in leading a healthy lifestyle, but they may not have enough knowledge or understanding about the importance of preventive health measures like immunization. In addition, lifestyle behaviors such as staying safe from STDs, maintaining good oral health, and avoiding drugs/alcohol are considered extremely/very important by a greater number of teens than more clinical aspects of health care such as seeing a doctor, taking vitamins, and getting flu shots and other recommended vaccines.

We also learned that despite the work that has been done by various organizations to educate parents and the public on immunization, there is still a great deal of misinformation about vaccines in the public domain and social media has proliferated that. Nearly six in 10 parents (57 percent) and teens (57 percent) have some safety concerns about vaccines, and nearly five in 10 parents/teens (45 percent and 47 percent, respectively) have concerns based on what they've read on social media.

**Was there anything that surprised you about parents’ views on adolescent preventive care and/or the well visit?**

We were surprised at the number of parents (41 percent) who believe that their teens should only see a health care provider when he/she feels sick. Preventive care and annual well-visits are important at all ages and provide an opportunity for routine and catch-up immunizations as well as discussion on various age-specific health topics. By adhering to annual well-visits throughout adolescence, parents are helping to establish a behavior that teens will ideally continue into adulthood.

**Was there anything that surprised you on the adolescents’ views of their parents’ involvement in their health care?**

We were interested to learn that the clear majority of teens (89 percent) are comfortable asking their parents questions about their health, and 76 percent say they need their parents/guardians to help them stay healthy.

**How might your findings be application to efforts engage parents in efforts to increase uptake of the well-visit?**

Our findings underscore the need for ongoing communication with parents and adolescents about the importance of the well-visit, immunization, and preventive health. We encourage health care providers to set up reminder systems to alert
parents and teens to make appointments for well-visits – especially at 11-12 and 16 years of age when vaccinations should be given – and processes to reach out to parents if vaccines are missed.

Unity offers several resources focused on immunization, including:

- A validated intervention program for immunizers that helps improve delivery of a confident, concise, and consistent recommendation for routinely recommended vaccines to adolescents. See the Unity website to learn more about this Three Cs program, which includes Continuing Medical Education credit for providers.

The strategies presented are based not only on what we learned from the survey, but from experiences and promising practices identified from a panel of adolescent health and immunization experts. The white paper, a collaboration of the group’s members, liaisons, and invited experts, outlines the INSPECT (Immunization Neighborhood, Sharing, Platform, Educate, Champions and Talk) Imperatives.

In addition, as outlined in the Society for Adolescent Health and Medicine’s recent position statement, Establishing an Immunization Platform for 16-Year-Olds in the United States, and the Adolescent Immunization Initiative white paper, Rationale for an Immunization Platform at 16 Years of Age, providers should establish a routine preventive visit for 16-year-olds, creating an opportunity for immunization and discussion of health care topics uniquely relevant to older teens and young adults.

How are you using the research? What are your next steps?

The research is being used to inform our continued educational efforts with organizations serving and connect directly with health care providers, parents, and teens to improve adolescent health. Our press release and infographics on the survey results include our findings as well as important reminders for parents and health care providers based on what we learned. We will continue to share these materials on our website, our Facebook page, and via Twitter. In addition, Unity recently completed a global teen health survey, and we look forward to comparing those results with the U.S. survey results to look for both similarities and differences that warrant further discussion. We also hope to use these survey results as a benchmark for additional research in the years ahead.
Integrating Family Engagement into Medical Home Implementation: Lessons Learned and Implication for Adolescent and Young Adult Engagement

Alexandra Kusnetsov, RD
Manager, Children with Special Needs Initiatives
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Maternal and Child Health Block Grant guidelines encourage Title V programs to sustain and diversify family partnerships through implementation and documentation of family engagement activities. Family engagement is a key function of the patient- and family- centered medical home, the standard of care for all children, adolescents, and young adults. The National Center for Medical Home Implementation (NCMHI), a cooperative agreement between the American Academy of Pediatrics and the Maternal and Child Health Bureau, provides technical assistance and support to Title V programs across the country in implementation of family engagement to enhance provision of health care within a medical home. At the end of this article, there are some resources that can provide some preliminary technical assistance on meaningfully incorporating family engagement within programmatic efforts.

The NCMHI completed two projects focused on enhancing family engagement in the context of medical home implementation, including a quality improvement project and a community-based initiative. The quality improvement project convened multidisciplinary core improvement teams which included a parent/caregiver partner. The community-based initiative focused on collaboration with bicultural peer navigators to enhance access to medical homes for diverse and medically underserved families. Although the methodology for these projects differed, implementation strategies and lessons learned have broad implications for Title V programs looking to engage families, young adults, and other community stakeholders in their efforts, including the following:

- **Ask, “What’s in It for Them?”**
  Consider the motivation for a family member, caregiver, or young adult to partner with your organization on a project. This motivation may be different from your project’s mission and may help to improve the project’s goals and build a trusting relationship between professionals, families, and other stakeholders.
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- **Clearly Identify Roles and Responsibilities**
  At the beginning of any project that will engage parents, caregivers, or young adults, clearly identify each team member’s roles and responsibilities. Outline expectations for families, caregivers, young adults, public health professionals, clinicians, and others involved in your project. Consider creating a job description for each team member.

- **Provide Incentives**
  Offer families, caregivers, and young adults incentives for participating and engaging in your project. This can include financial stipends, childcare services, food, support for transportation, networking, and professional development opportunities.

- **Engage in Innovative Communication Strategies**
  Families, caregivers, young adults, clinicians, and Title V public health professionals are all busy and may not be available to meet in person. Identify innovative strategies to promote communication and collaboration between these multidisciplinary teams, including the use of social media, Skype, email, and/or a shared online work space.

- **Partner with Motivated Community Members and Cultural Brokers**
  Whether you are working on quality improvement, a community-based project, or another initiative, consider partnering with bicultural community members (families, caregivers, young adults). These individuals know their communities best and can effectively represent community needs, challenges, and opportunities.

Additional resources include the following:

- [Enhancing Family Engagement Through Quality Improvement](#)
- [Family Engagement Quality Improvement: A “How-To” Implementation Toolkit](#)
- [Parent/Caregiver Partner Position Description](#)
- [Fostering Partnership and Teamwork in the Pediatric Medical Home: A “How-To” Video Series](#)
- [Back to Basics: Meaningfully and Effectively Engaging Families in Pediatric Practices and Systems](#)
- [Lessons Learned from a Community-based Project: Strategies to Enhance Access to a Pediatric Medical Home for Diverse Communities](#)

For additional assistance and support with medical home implementation for children and adolescents, contact [medical_home@aap.org](mailto:medical_home@aap.org) or visit [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org). Sign up for the NCMHI e-Newsletter for monthly tools and resources to assist with family engagement and medical home implementation.
Over the last 12 years, the Boston Children’s Hospital Community Asthma Initiative (CAI) has served over 1,900 patients and their families, providing more than 2,600 home visits in the Boston area. These patients have high-risk asthma that requires multiple courses of steroids or frequent hospitalizations or emergency department visits. Of these patients, 49 percent of patients are Hispanic or Latino, and 44 percent are African American, 78 percent are on Medicaid, and 64 percent have an annual family income of less than $25,000. In addition, almost a quarter of the patients are monolingual Spanish speakers.

When a patient is hospitalized or in the emergency department for an asthma exacerbation, a CAI nurse or Community Health Worker (CHW) meets with the patient and his or her family to offer them enrollment in the Community Asthma Initiative, assess his or her needs, and provide initial education and support. A CHW then meets with the youth and family in their home to better understand their needs, their health beliefs about asthma, the medications used to treat it, and the barriers they face in controlling the youth’s asthma. The CHW can then provide tailored asthma education, focusing on the family’s individual needs, assess for adherence to controller medications, and conduct a home environmental assessment to look for triggers throughout the patient’s home. The CHWs also deliver supplies that can be helpful in remediating triggers, including a HEPA vacuum, dust mite-proof mattress and pillow encasements, and materials to control or prevent pest infestations. They also help coordinate follow-up with the medical home and specialists, if needed, and advocate around housing conditions or other social needs. CHWs provide continued support to the patient and family during three or more home visits and additional follow-up by phone or in-person over 12 months.

Throughout the process, the CHWs and the nurse engage with youth, patients, and families directly with the goal of better asthma control and improved quality of life.

In addition, the Community Asthma Initiative engages with parents/guardians, as well as other community members, through twice-annual Community-Family Advisory Board meetings. At these meetings, parents/guardians, and community members provide CAI staff and invited guests feedback on current projects and areas of need in the community. CHWs give advisory board members important program updates about community events and resources, as well as other opportunities for youth in the community, such as after-school activities, sports, and job programs. (continued on the following page).
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CAI has identified some strategies for family engagement:

1) Involve family members face-to-face and encourage them to give feedback through the advisory board.
2) Support families to advocate for improvement in asthma care and management in school and community settings.
3) Help families to better understand asthma and environmental triggers as parent representatives in their communities.

Actively engaging parents and youth can improve families’ interactions with the healthcare system and community agencies.

To learn more about the information presented here, please visit our website or contact Rebecca Penzias, Research and Program Coordinator for the Community Asthma Initiative, at rebecca.penzias@childrens.harvard.edu.

CoIIN Corner

Check out exciting updates from the AYAH CoIIN’s Minnesota and Wyoming State Teams!

**Minnesota:**
The Minnesota CoIIN team continues to meet quarterly to carry out three overlapping strategies:

- **Marketing the well-visit to adolescents** by partnering with a statewide EPSDT outreach effort managed by Hennepin County Public Health (local public health agency) and a marketing agency (Haberman). Haberman recruited young people to participate and inform the campaign through brainstorming, idea generation, storytelling and review of two possible campaigns.

- **Improving quality of care** through a pilot quality improvement effort with clinics in an integrated health care organization (Health Partners and Park Nicollet). They’ve started by assessing current capacity through youth patient satisfaction surveys and are developing a survey of providers, clinic assessments led by the CoIIN Youth Reps (piloting the University of Michigan and Adolescent Health Initiative’s Youth-led Health Center Assessment tool), clinic ratings and training of providers and staff on youth development, youth-friendly care, and how to communicate with youth. The CoIIN Youth Reps will partner with the clinics through the clinic assessments and trainings. As part of this, they will create a guide with tips to help providers work effectively with youth.

- **Improving policy.** Through partnership with the MN Medicaid program (MN Dept. of Human Services), Early and Periodic Screening, Diagnosis and Treatment (EPSDT) policy was changed to adopt Bright Futures guidelines starting October 1, 2017, for annual adolescent well-visit, universal HIV screening (youth age 15-18), and mental health screening (required not just recommended). To support this policy change, the team is reaching out to providers through professional associations and local public health to raise awareness and provide technical support. In addition, the CoIIN team is working with Abigail English (Center for Adolescent Health and the Law) and HealthPartners legal counsel to clarify and summarize minor consent and confidentiality policies.
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Wyoming:
The Wyoming Adolescent and Young Adult Health CoIIN Team has been working hard developing and launching both a youth and young adults and a parent/caregiver survey to determine the reasons that young people don’t get their well-visits. The YAYA survey was developed, tested, and edited by young people for young people. We are excited to begin assessing results of these surveys!

Selected Resources from the AYAH Center

Check out the AYAH Center’s Family Engagement Resources!

- Family Engagement in Title V Programs (AMCHP) is a survey about family engagement policies and practices in Title V MCH and CSHCN programs. The survey findings offer a snapshot of strategies to support meaningful family engagement, effective and innovative practices, and areas for improvement and technical assistance.

- Reaching and Engaging Millennials in Health Care: Notes from the Field (AYAH-NRC/Young Invincibles) is a presentation that was given at the first AYAH Center CoIIN Summit in 2015 during Young Invincibles’ Healthy Young American campaign to educate, engage, and enroll young adults into health insurance. Additional information on this campaign include key messaging and outreach best practices.

- COMING SOON! A Family Guide to the Adolescent & Young Adult Well Visit (AYAH Center) is a promotional and educational tool for caregivers of adolescents and young adults to promote the importance of the well visit.

From the MCH Community

Protect & Connect with Your Teen (UNITY): As a parent, what you say matters to your teen or young adult. From staying up-to-date on vaccinations to preparing your adolescent for conversations with his or her health care provider, you can help protect your child by influencing important health decisions and behaviors.

Download this factsheet for tips on communicating with your teen and to read on how you can help protect your child by influencing important health decisions and behaviors. To learn more about ACIP-recommended vaccines for adolescents and young adults and to see if your child is up-to-date on immunizations, talk with your child’s health care provider.

Engaging Diverse Populations Case Study and Family Engagement Case Study (AMCHP): The case study reports provide examples of engaging families and engaging diverse populations from a total of five states.
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Upcoming Newsletter Issue

Stay tuned for the December/January issue:

Infusing the Adolescent Well Visit into other Initiatives!

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