



The Status of Youth-Friendly Healthcare

[Suburban Area] Findings & Recommendations

Spring 2015

Overview of ICAH

** Note: Specific locations in this report have been redacted for the sake of participant anonymity.*

The Illinois Caucus for Adolescent Health (ICAH) is a network of empowered youth and allied adults who transform public consciousness and increase the capacity of family, school and healthcare systems to support the sexual health, rights, and identities of youth. At ICAH, we envision a world in which all young adults in Illinois use their power to achieve health and well-being in their own lives and for their communities. Within this work we hold the following eleven values:

- Youth-Centered
- Knowledge
- Rigor & Vigor
- Justice Orientation
- Sex Positivity
- Self-Care
- Empowerment
- Trauma and Cultural Awareness
- Safe-Space
- Asset Based
- Excellence

In 2012, ICAH launched a three-year organizing strategy with youth leaders and adult allies in healthcare, family and school systems to wage cultural advocacy for change in the way people parent, teach and treat students at home, at school and at the doctor's office respectively.

This strategic plan not only pushes ICAH's vision forward, but also clarifies eleven values that are central to our functioning and a theory of change that breaks down barriers to access and education.

These pathways for change serve a dual purpose as social media hashtags to start intentional conversations and debates about the following crucial issues through which public consciousness can be changed:

#YouthVoice: Increase opportunities for youth decision-making and leadership within family, school, and healthcare systems.

#AdultAllies: Increase the capacity of adult and youth allies to foster mutually respectful relationships.

#SexEdSaves: Increase access to sex-positive, inclusive, and developmentally appropriate information around sexual health, identity, and rights of youth.

#HealthAccess: Increase access to sexual healthcare, information, and resources in a culturally-relevant and youth-friendly way.

#SafeSpace: Increase access to safe relationships and environments that support health and positive self-perception.

#NoShame: Reduce stigma and shame around youth sexuality and sexual decision-making.

We believe that an organized effort for cultural shifts in beliefs about young people's rights and capacity to make decisions about their bodies will both impact policy and the direct experience that young people encounter in accessing sexuality education and sexual health care. We believe that this process involves both raising the capacity of youth AND adults to partner for change.

The Networks of ICAH

As an integral part of ICAH's three-year organizing strategy, ICAH houses three networks covering school, family, and healthcare systems. These network areas were selected based on the institutions and systems that young people interact with most frequently and consistently. Through intentional base-building, network members work to increase the capacity of adults to become **#AdultAllies** and to effectively partner with young people in order to improve programs, policies, and procedures that directly impact their lives.

In this model, and in partnership with ICAH's Youth Leadership Council to ensure **#YouthVoice**, ICAH gathers professionals in each network to discuss common trends, utilize relevant research to inform their work, and create change in these systems by engaging in concrete actions that advance our work.

ICAH's Healthcare Network

As one of ICAH's three networks, the Healthcare Network is focused on transforming public consciousness and increasing the capacity of healthcare providers to support the sexual health, rights, and identities of youth. Healthcare was selected as a critical system on the premise that young people will interact with healthcare providers, clinics, and insurance policies in some capacity during their lives.

After discussion about trends in the field, ICAH's Healthcare Network prioritized increasing the standard of training and competency of professionals as their area of focus to ensure youth friendliness in clinics, hospitals, and residency programs. In order to create a world in which young people are safe, healthy

and affirmed, ICAH's Healthcare Network works on **#HealthAccess** in a **#SafeSpace** with **#NoShame**.

This includes addressing current gaps in provider guidelines and creating a tool that can be utilized in the aforementioned areas. As a way to capture the variety of ways in which young people may interface with the healthcare system, the Healthcare Network emphasizes work with Pediatricians, Family Medicine practitioners, and Obstetrician-Gynecologists.

Previous Strategies and Accomplishments

During these discussions emphasizing ways to increase youth-friendliness in healthcare, the idea of a **competency flashcard deck** began to take shape. After four months of planning through youth-adult collaborations, the Network identified the six core areas that a provider would need to be competent in and then, using the existing scenarios within ICAH's Talk the Talk card game as a starting point, wrote real life scenarios faced by young people and providers and paired them with youth-friendly and medically accurate responses. The six competency areas include:

- Sexual Health
- Sexual Rights
- Sexual Identities
- Healthy Relationships
- Sex Positivity
- Trauma Awareness

In order to gather healthcare professionals across the three specialty areas of focus to share knowledge, skills, and tools and launch the new Youth-Friendliness in Healthcare Flashcards, ICAH's Healthcare Network held a **Youth-Friendly Healthcare Town Hall** on April 25th 2014 at Lurie's Children's Hospital. The Town Hall focused on uncovering and aligning standards of adolescent care with Pediatricians, Family Medicine practitioners, and Obstetrician-Gynecologists serving adolescent patients. The Town Hall highlighted best-practices recommendations including providing care that was trauma-informed, non-judgmental and used motivational interviewing skills as a way to promote youth-centered decisions and patient-provider conversations. The Town Hall was concentrated on reaching out to Chicago-based medical providers and had around 25 practitioners present. Beyond the Town Hall there has been an increase in recognition of ICAH's work with healthcare professionals and **over 250 Youth-Friendliness in Healthcare Flashcard decks have been purchased by practitioners**. In 2015 ICAH attended the National Reproductive Health Conference in Orlando, Florida where specific Youth-Friendliness in Healthcare Flashcard decks were created and launched for 20 states, allowing this resource to be available nationally.

Through the tremendous efforts and work of the Healthcare Network, we have developed a strong presence in Chicago and have begun reaching out to a range of providers. Based on our strategic plan that includes the greater Chicagoland area, Springfield, and East St. Louis, we expanded our network efforts to the [suburban areas around Chicago] in the fall of 2014.

Initial Approach

ICAH's initial approach for organizing in [unnamed suburban area] focused on outreach and partnership development with the area's hospitals and local collaboration, and [an organization that focuses] on increasing the establishment of medical homes and primary health care providers by community members.

On March 11, 2015 ICAH's Healthcare Network hosted an informational session at [a hospital in Illinois]. The session held two purposes: to facilitate a training focusing on creating adult allies in the healthcare system, and to hold a discussion surrounding the barriers that healthcare providers are seeing in the area when it comes to healthcare access.

Both outreach and informational session efforts lacked sufficient response from providers that would help inform and expand ICAH's organizing efforts surrounding youth-friendly healthcare. Based on this information, a **Proposal for Modification was approved allowing [the suburb's] efforts to focus on information gathering and environmental scanning** instead of the previous Town Hall and informational session approach.

Focusing in – [Specific Suburban Area]

With the pre-existing connections and knowledge of Healthcare Network member Dr. Karen Scott, MD, FACOG as well as the information gained from our initial approach, the Network took a new strategy that moved away from the Town Hall model used in Chicago the previous year. Instead, **the Network decided to invest the spring of 2015 gaining information surrounding the environment and community experiences of [suburban area] young people and providers to inform future organizing efforts.** With this new goal, the Healthcare Network advocacy strategy became rooted in holding conversations and gathering information among young people and the area's healthcare providers through one on ones, focus groups, and targeted outreach.

Focus groups with young people would allow for stories to be shared about people's experiences with accessing healthcare in the [suburban area]. Focus groups with providers would also be helpful and illuminate the current ways in which they see young people in their practice and relevant barriers they can

identify. **With this new strategy, eight weeks were dedicated to organizing and holding these conversations that would be used to inform a future organizing platform.**

Accomplishments and Findings

The Healthcare Network was able to hold **two provider focus groups and one youth focus group**. The selection of the focus group participants and location was based both on research surrounding where young people were reported to seek services most often, as well as established connections to youth workers with on-going groups for young people.

Cultivating #YouthVoice

Through collaboration with [a] High School Childcare Center and their director [redacted], **ICAH's Healthcare Network held an hour long focus group with eight of the center's pregnant and parenting young people on May 6th, 2015**. During that focus group ICAH listened to stories of young people surrounding **where and how frequently they access care as well as what their healthcare experience and provider relationships look like**.

Pregnant and Parenting Youth Focus Group Findings

- **Inconsistency of healthcare provider availability**
 - o While participants voiced that they had previously sought services at [local clinics], there was an overwhelming shared experience of having inconsistent provider availability. One young parent expressed that they had a total of three doctor transitions over the course of their pregnancy.

- **Barriers to effective healthcare experiences and access**
 - o Multiple participants expressed long wait time both on the phone while making appointments as well as at clinics after checking in for their scheduled time. Some young people spoke to waiting for over an hour for a scheduled appointment, while others were turned away completely if they were a couple minutes late.
 - o Language barriers were also present for young people that had difficulty understanding clinic workers or providers, even during childbirth experiences
 - o Insurance also played a role in young people being able to access care and often meant they sought care at an Emergency Room versus having the opportunity to develop a primary care provider.

- **Incomplete and inaccurate medical information and services**

- An overwhelming majority of the young people stated that their doctors had performed incomplete health screenings and exams of their child that resulted in future emergency room visits due to missed information and warning signs during visits.
 - Many young parents also expressed that they were given inaccurate and incomplete information surround contraceptive care. This included not informing the young person of various possible side effects of birth control as well as not clearly communicating contraceptive options, including not being on birth control.
- **Use of shaming and judgmental language by providers**
 - Young people experienced severe shaming surrounding their parenthood including being referred to as a “Child having a child” and being addressed with statements like “You’re not going to have another kid for a few years, right?” A vast majority of the participants reported that even if actual providers were respectful, they had to interact with clinic staff that were disrespectful and dismissing.

Participants of the pregnant and parenting young people focus group allow shared their thoughts on what providers and clinic staff could do to improve their healthcare experiences and increase their ability to access quality care. Shared themes surrounding suggestions included **increased youth-friendliness among healthcare providers and having care that centers informed-choice and transparency**. Specifically, young people gave the following feedback:

- **Increased youth-friendliness among healthcare providers**
 - Positive greetings and smiles go a long way!
 - Non-judgmental language surrounding parenthood and sexuality helps start conversations and breaks down barriers.
- **Promote care that centers informed-choice and transparency**
 - Don't force or trick young people to do what they don't want by not disclosing full or complete information. Actively listen to what young people are explaining to you to promote positive and effective patient-provider partnerships in the healthcare of young people.

Seeking #AdultAllies

Through conversations with adult community members who worked with young people, the spaces that continued to be presented as locations that were accessed by young people for healthcare services were [two locations]. While the Healthcare Network reached out to both service providers, we ended up providing **two separate focus groups on April 1st and 29th that captured over 22 provider voices of [a local clinic] across specialties**. These focus groups were held during protected staff meeting time and served as an informal way for

ICAH to gain perspective within the limited time constraints of provider schedules.

Provider Focus Group Findings

During provider focus groups, two main themes were present when discussing barriers practitioners faced when providing healthcare services to young people: **lack of access to accurate sexual health information and parental pressure or interference when seeking services.** Focus group participants specifically addressed the following barriers:

- **Comprehensive sex education is not reaching all young people even though it is provided in 9th-11th grade classrooms**
 - o There is still a focus on abstinence that may include conversations about condoms without discussing how to use them effectively
 - o One doctor stated that “high risk” young people are the ones not getting the information. Specifically, this provider referred to young people that were absent from or taken out of school lacking alternative spaces to access sexuality education and healthcare information.
 - o Providers working at the juvenile detention center stated that young people were often unaware that their school had offered sex education. Providers shared experiences of working with young people that had not previously had the opportunity to access healthcare and became newly informed of pregnancy, healthcare information, and STI/HIV status upon arriving at the center.
- **There is a lack of information about the STI/HIV prevalence present in the community**
 - o One doctor reported a high number of 19-21 year old male-identified young people being HIV+
 - o Several doctors spoke to the reason behind these numbers being linked to accurate STI/HIV information not being present or seen as important in the community
- **Parents can be a source of pressure for young people to be on birth control, specifically the DEPO shot, whether young people are sexually active or not**
 - o One provider told a story of an interaction with a 14 year old young person and their parent where the mother brought her in specifically for the DEPO shot.

Providers of the [local clinic] also highlighted ways that they were navigating these barriers when providing healthcare to young people. Themes that arose during this barrier navigation focus group discussion included: **promoting the confidentiality and desires of young people and building strong patient-provider relationships.** While these techniques were present, they were less generalizable

among all group members and were instead only voiced by a few participants. Providers that did express barrier navigation skills emphasized the following:

- **Protect young person's alone time with provider**
 - o Providers were aware of needing to protect patient confidentiality by asking parents to leave the room for part of the exam once the patient reached the age of 12
 - o Providers understood that parents may read the printed patient plan or visit summary and ensured to protect confidentiality when writing appointment summaries

- **Be curious and build relationships**
 - o Providers spoke to asking open-ended and non-judgmental questions to understand where the young person got their information. There was also a mention of making the appointment more conversational and less about conveying expert knowledge by the provider

- **Increase access to resources when possible**
 - o The involvement of case managers and access to behavioral health services as a way to support young people accessing care

Conclusions and Recommendations

During the May 2015 Healthcare Network meeting, intern Kassy Podvin presented the focus group findings and information highlighted in this report. As a group, members collectively agreed that continued work in [this specific suburban area] is needed and composed the following recommendations to help guide that work.

Sustaining a targeted bottom-up approach

While the Healthcare Network remains focused on engaging with the three specialty areas of Family Medicine practitioners, Pediatricians, and Obstetrician-Gynecologists throughout the entire [suburban area], current organizing efforts should be redirected to alternative entry points and remain targeted on the [two-county area]. This approach will allow for relationships and knowledge of ICAH's work to grow and will provide a platform for future provider engagement in other [suburban areas]. Organizing should focus on cultivating initial relationships with community organizations in addition to healthcare focused organizations, progressive professional healthcare networks or unions, medical staff, and school nurses to deepen ICAH's knowledge of the area's resources and landscape surrounding youth-friendliness in healthcare.

Building Youth-Adult Partnerships

A central part of ICAH's continued organizing in the [suburban counties] should be focused on cultivating relationships with the area's young people and the adult allies that work with them. This work will need to be informed by additional outreach and one-on-ones to identify current community members that have existing positive partnerships with young people in the area or have the ability to move and influence others in the community. Relationships with young people may be strengthened by engaging area youth with ICAH materials and workshops within schools and community spaces. Lastly, current venues for healthcare provider feedback, specifically from young people, should be identified. With the information and relationships gained across these avenues, organizing efforts should begin to work to create spaces for medical staff and providers to interface with young people in ways that allow for youth storytelling and adult ally skill building for providers.

Investment in youth involved in the juvenile justice system

Based on the focus group feedback, as well as additional knowledge provided by network member Christine Head, there has been expressed momentum and concern for the health of the area's young people that have been involved with the juvenile justice system. Collaboration with professionals in this field that have an existing investment in the lives of young people, and who have identified health access as a need, is a promising entry point for ICAH's organizing efforts.

Offering Creative Incentives

As part of ICAH's work with providers and medical staff, there should be a creative focus on incentive development beyond and in addition to the establishment of Continuing Medical Education (CME) credit offerings. This incentivized approach would work in partnership with ICAH's Education Coordinator to provide specialized professional development or certificates that would help promote youth-friendliness in healthcare. Marketing and language surrounding these incentives should be framed in ways that are more relatable to provider populations while also aligning with ICAH values.