











# LGBTQ INCLUSION IN CHILDREN'S HOSPITALS:

LESSONS LEARNED FROM THE HEALTHCARE EQUALITY INDEX



# LGBTQ Inclusion in Children's Hospitals: Lessons Learned from the Healthcare Equality Index

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# **CONTENTS**

Foreword	5
Introduction	
Background	
Methodology	8
Key Findings	8
Patient Non-discrimination & Staff Training	8
Patient Services & Support	12
Related Reports	14
Employee Benefits & Policies	
Patient & Community Engagement	20
Resources	21
Endnatas	0.0

Photos from Arkansas Children's Hospital, Children's Hospital of Philadelphia and Ann & Robert H. Lurie Children's Hospital of Chicago



#### **FOREWORD**

Dear friends,

To say that 2020 has been a year like no other in our history is probably the understatement to end all understatements.

With the global eruption of the COVID-19 pandemic, we've seen the effects of sustained fear and isolation on children, adolescents and adults. **Depression** and **anxiety** are on the rise, as is **substance use and abuse**. Decreased physical activity and social distancing lead to **unhealthy perceptions of weight** and **self-image**, as well as intense **loneliness**. Perhaps worst of all, we've seen a marked increase in patients and families who are **too afraid to seek out care and support** that they so desperately need.

All of which simply underscores how vitally important the lessons learned from the Healthcare Equality Index truly are...because the list of symptoms experienced by a nation under quarantine, almost perfectly mirrors the top health concerns impacting LGBTQ+ youth and families on a daily basis.

It's both shocking and heartbreaking to realize that what so many of us see as extreme fallout from unprecedented circumstances reads like a roadmap through the everyday landscape of our LGBTQ+ community's health needs. And I am so grateful to the Human Rights Campaign Foundation for gathering together the most important lessons learned from all of the children's hospitals and healthcare facilities that have participated in the Healthcare Equality Index.

I am so proud of Boston Children's role as a HEI LGBTQ Healthcare Equality Leader, and even more proud of the extraordinary work that all of us are doing to deepen our understanding of what our LGBTQ+ patients, families and employees need, and bridging the gaps in their support and care. The more we understand, the better equipped we are to evolve with those needs, and eventually get ahead of them instead of striving to catch up.

Whether we're working to enhance the health of LGBTQ+ patients and families, engaged in the groundbreaking research that will play so crucial a role in defining the future of LGBTQ+ health-care, or providing education around the inherent respect of honoring a person's gender identity, the work we are all doing in this area is essential and so meaningful.

I urge you to read this report thoroughly, and to embrace the lessons within. We all know that we can do more when it comes to creating a safe and welcoming culture for all. We know that we can do more when it comes to providing care that is respectful, compassionate and inclusive. Learning from each other is the first step.

Warmest regards,

Sandra L. Fenwick

Chief Executive Officer Boston Children's Hospital

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#### INTRODUCTION

ince its inception, the <u>Healthcare Equality Index (HEI)</u> has become the nation's leading tool to measure and benchmark progress in affirming care for LGBTQ people in healthcare facilities. The HEI helps hospitals and other healthcare facilities adopt inclusive policies and practices that enable them to better serve their LGBTQ patients, visitors and employees.

Children's hospitals are regular participants in the HEI, with nearly 50 of them participating over the past three years. As children's hospitals, these organizations recognize the importance of ensuring the equitable treatment and inclusion of LGBTQ youth who come to them as patients, LGBTQ family members of children receiving care, and LGBTQ employees working in their institutions. Many children's hospitals score highly on the HEI and earn the designation of LGBTQ Healthcare Equality Leader, a title reflecting their commitment to inclusive policies and practices.

HRC encourages all children's hospitals to learn more about LGBTQ inclusion and consider participating in the next HEI.

# **BACKGROUND**

LGBTQ youth present for care at children's hospitals across the country, seeking either routine health care or care related to their sexual orientation or gender identity. An estimated 10.4% of youth in high schools across the United States identify as lesbian, gay, or bisexual (LGB), 2% identify as transgender, and 4.2% are unsure of their sexual identity, according to the Centers for Disease Control: 1 As institutions that care for LGBTQ youth, it's important that children's hospitals be attuned to LGBTQ patients' specific health care needs and concerns. Mental health and psy-

24% of transgender youth have skipped school because they felt unsafe, 37% have been bullied on school property and 42% have attempted suicide. Transgender youth are also more likely than cisgender youthto report violence victimization, substance use and suicide risk.

chosocial safety are major concerns for many LGBTQ youth, especially those who are transgender. HRC Foundation's internal analysis² of the Youth Risk Behavior System found that 24% of transgender youth have skipped school because they felt unsafe, 37% have been bullied on school property and 42% have attempted suicide. Transgender youth are also more likely than cisgender youth to report violence victimization, substance use and

suicide risk.<sup>3</sup> Children's hospitals should ensure that they create a welcoming and safe space for all of their LGBTQ patients, including transgender youth. Hospitals should have LGBTQ-inclusive patient non-discrimination policies, be teen-friendly, and ensure that health providers do not make assumptions about sexual orientation and gender identity. LGBTQ-inclusive policies and practices should be paired with ongoing staff training in LGBTQ patient-centered care.

Children's hospitals must also prioritize effective interpersonal communication between health care providers and LGBTQ patients. Very few LGBTQ youth are "out," or have otherwise disclosed their sexual orientation and gender identity to their pediatricians or primary care providers, according to a 2018 HRC Youth Survey; 67% of sexual minority youth and 61% of gender minority youth were not out at all to any of their healthcare providers. This lack of trust and disclosure can serve as a barrier to effective communication for care and harm prevention messaging for LGBTQ youth. For youth that are not out, the fear of disclosure and the potential of discrimination may keep them from seeking the care they need.

In addition to understanding the clinical concerns of LGBTQ youth, children's hospitals also need to be familiar with and sensitive to interacting with a variety of family structures. Although estimates vary, as many as 2 million to 3.7 million U.S. children under age 18 may have a lesbian, gay, bisexual or transgender parent, and nearly 200,000 are being raised by same-sex couples.<sup>5</sup>

Finally, a children's hospital cannot be fully LGBTQ inclusive without ensuring that its policies and benefits are also fully inclusive of LGBTQ employees. Hospitals are among the top industries where LGBTQ people work: LGBTQ people make up 9% of workers in hospitals, compared to just 5% of all workers nationwide. LGBTQ employees play a vital role in healthcare organizations, ensuring LGBTQ patient-centered care by informally educating their co-workers about patient concerns, offering feedback about organizational policies and practices, and conveying to the local community their organization's commitment to equity and inclusion. It is critical that LGBTQ employees, like LGBTQ patients and families, receive equal treatment.

#### **METHODOLOGY**

While the vast majority of the HEI-recommended policies and practices can be equally applied to all healthcare facilities regardless of patient population or services provided, children's hospitals have some unique experiences and issues surrounding LGBTQ inclusion. To better understand these issues, HRC convened a focus group of experts in LGBTQ health and diversity and inclusion leaders from children's hospitals that regularly participate in the HEI. Participants were geographically representative and came from various professional disciplines, including social work, diversity and inclusion, divinity, ethics, nursing, medicine and law.

The focus group met in person and via internet meeting platforms for two days on January 29th and 30th, 2019.

Focus group participants were asked to discuss their unique experiences related to LGBTO inclusion in children's hospitals, as well as how the HEI criteria might apply differently in children's and adult hospitals. The discussion was structured around the four criteria areas of the HEI:

- Non-discrimination & Staff Training
- II. Patient Services & Support
- III. Employee Benefits & Policies
- IV. Patient & Community Engagement

#### **KEY FINDINGS**

# **Patient Non-discrimination & Staff Training**

The Patient Non-Discrimination & Staff Training criteria of the HEI represents policies and practices that are considered foundational to LGBTQ patient-centered care. This criteria calls for:

- 1. A written patient non-discrimination policy that includes both "sexual orientation" and "gender identity or expression;"
- 2. A written visitation non-discrimination policy or an equal visitation policy;
- 3. A written employment non-discrimination policy that includes both "sexual orientation" and "gender identity or expression;"
- 4. Communication of these policies to both patients and employees; and
- 5. Staff training in LGBTQ patient-centered care.

# **Discussion**

Participants reported that general patient and employee non-discrimination policies in children's hospitals followed their counterparts in adult hospitals; they did not feel that there were significant special considerations for children's hospitals. However, they identified several unique considerations and challenges related to LGBTQ-inclusive visitation policies in children's hospitals.

#### **Patient Non-Discrimination Policies**

One care issue related to non-discrimination that arose in the focus group was the topic of conscientious objection and/or refusal of care to sexual and gender minority patients. Health professionals have the option for conscientious objection and/or refusal of care based on their personal or moral beliefs, though some disagree and have considered making the practice unethical. Focus group participants discussed that although conscientious objection had been mentioned in many of their institutions, most had not universally incorporated it into a balanced patient and employee "bill of rights and responsibilities." One participant noted that their children's hospital reviewed its religious exemption policy and made those exemptions consistent with overall non-discrimination policies.

#### Visitation Policies

Visitation policies in children's hospitals present unique challenges for LGBTQ patients, families, and visitors. Focus group participants reported various definitions of "family" used in their hospitals' visitation and other policies. Several participants noted that their organizations had taken steps to standardize visitation policies.

However, across the board, participants agreed that families of diverse structures — blended, single parent, same-sex couple, mixed race parent/interracial couple, families with different last names —

Focus group participants further highlighted that children and youth can be uniquely vulnerable in the hospital setting if visitation policies cut off their support systems.

were more likely to encounter difficulty in obtaining support and treatment than those in heteronormative, traditional family structures. Participants pointed out that assumptions of what constituted a family were driven by implicit bias based on perceived characteristics of the presenting family unit. For example, parents with children of discordant race often were wrongly assumed to have an adoption history.

Participants also reflected on the historic practice of weaponizing social work services to investigate families with alternative parental structures. They discussed how their health systems have reacted to families with same-sex parents, often with the assumption that these parents were foster or adoptive parents. Focus group participants also commented on the

negative effect of hospital employees' reflexive policing behaviors, demonstrated by "calling social work" to determine decision-making status for parents in non-traditional family structures.

Focus group participants further highlighted that children and youth can be uniquely vulnerable in the hospital setting if visitation policies cut off their support systems. Children and youth can be denied access to supportive others in some instances (e.g., emergencies, health crises) and remain separated from romantic and emotional partners who may hold significant support roles in their lives.

A unique issue raised in relation to children's hospitals' visitation policies was the role of the patient in visitation refusal. While adults have the right to choose their visitors, that role falls to the parents/guardians in most children's hospitals. However, some participants reported that, depending on the age, maturity and social circumstances of the patient, their hospitals allowed youth to refuse visitation, even by a guardian or parent. This can be important in cases where an LGBTQ youth has a parent that is unsupportive or when families are in conflict.

# ONE MOTHER'S STORY ABOUT HOW HER LOCAL CHILDREN'S HOSPITAL HAS HELPED HER TRANSGENDER DAUGHTER THRIVE

My name is Melissa and I am the very proud mother of 14-year-old identical twins, who happen to identify on different ends of the gender spectrum. My amazing daughter Conner happens to be transgender. She loves math, science and the color blue. Ice cream is her favorite food. She cries when she sees hurt animals or hurting people. She sticks up for the vulnerable and the voiceless. I've seen her give her ice cream cone to a homeless man, pack extra lunch for friends going through lean times, and organize a school lunchroom donation to our local food pantry. She is the kindest, bravest, and most authentic person I know, and she challenges me everyday to be a better person.

We were very relieved when we moved back to Ohio in 2015 and learned of the THRIVE program at Nationwide Children's Hospital. Within a short time of moving home, we were meeting with the Primary Care team and Conner was, at the time, their youngest patient in the program. I will never forget how our Nurse Practitioner introduced herself by identifying her name and pronouns, and asking my daughter what name and pronouns she would like them to use. From day one, the THRIVE program has validated our daughter for who she is, and worked with us to navigate the right path for her and our family.

I'm a mom, a nurse and a take-charge kind of person. It has been no easy feat to navigate a medical landscape that is still adding to long-term research and emerging future outcomes for transgender youth. There are unique challenges to having a child at the center of so many political battles, whose right to use the appropriate bathroom, or claim the rights of her full identity, or have the same opportunities as our son, her identical twin brother, are so hard fought.

The staff at the THRIVE program have always made us feel that we were partners in Conner's care. When we were unsure of how to move forward, they provided a safe space. When Conner decided to take a path that nobody had gone down before, we all held our collective breath and kept her moving safely forward. They have celebrated with us, advocated for us, and have worked with us to provide Conner with the tools she needs to be a happy and healthy teenage girl. And, we know that if harder times come, we have a medical team there to support us.

We had a recent unexpected stay as an inpatient at Nationwide Children's due to a field hockey injury. It's a horrible place to be in when the fear you have over your child's injury and unexpected surgery is complicated by dread that someone will misgender her or be careless with their remarks. I am so happy to report that our daughter was validated for her identity from the moment we arrived to her time of discharge several days later. I'd like to say that gender was a non-issue, and maybe it was for them. But, for us, their validation of Conner's identity made the stress of her initial pain and subsequent surgery so much easier. She was treated like a 14-year-old girl with an orthopedic emergency, except sometimes when I do think they made a point to be extra validating. Like the anesthesiologist who made a point to call her "Young Lady" several times and the nurse who made her his chocolate milkshake because what girl doesn't need a little extra chocolate when she's having a rough day?

I appreciate the work of the Healthcare Equality Index and how it helps organizations recognize the unique needs of this community and to adopt the policies and practices that make our children feel welcome. I am thankful to Nationwide Children's Hospital. Not only because of the THRIVE program, which recognizes how special kids like Conner are and whose exceptional staff have made our journey easier, but because we have felt recognized and validated throughout the hospital, not just in the THRIVE clinic.

#### **Staff Training**

Participants were also asked to discuss their experiences with training on LGBTQ patient-centered care. Many participants noted that their hospitals use a nursing-driven, family-centered care model in care delivery. One focus group participant pointed out the impact of heterosexual nurses' implicit bias against LGBTQ patients. Heterosexual nurses have been found to have among the highest rates of implicit bias against lesbian and gay patients, raising concerns about the effects of such bias in healthcare delivery to sexual and gender minorities.<sup>8</sup>

Several focus group participants shared examples of success in creating organization-level training on LGBTQ youth health concerns. One participant noted that their children's hospital established an annual transgender health conference. Another hospital is developing an interdisciplinary training session on LGBTQ health concerns. Other participants shared that they are developing their own staff and provider education programs to increase awareness of LGBTQ youth health disparities.

Unfortunately, others shared challenges encountered when promoting LGBTQ equality at their institutions. One participant mentioned experiencing pushback against LGBTQ-focused training as it was perceived to be taking the place of training for other vulnerable populations.

#### Recommendations

Focus group participants offered the following suggestions for children's hospitals to consider as they create policies and procedures which address LGBTQ patient non-discrimination and staff training:

- 1. Ensure all non-discrimination policies are LGBTQ-inclusive and recognize the unique role of children as patients. To be LGBTQ-inclusive, patient and employee non-discrimination policies should include the terms "sexual orientation" and "gender identity or expression" among the list of protected classes.
- 2. Ensure that your hospital's visitation policy is inclusive of diverse family structures and outlines when and if a minor patient can choose their visitors.
- 3. Training recommendations:
  - a. Create required trainings on LGBTQ and other underserved populations, and consider using an intersectional lens<sup>9</sup> to avoid real and perceived competition amongst vulnerable populations.
  - b. Conduct annual nurse training and offer LGBTQ-focused Continued Medical Education (CME) credit for providers.
  - c. Take low-hanging fruit opportunities. For example, prioritize engagement of frontline staff and providers, and those willing and personally affected, to assist with volunteer education throughout the organization.
  - d. Conduct more diverse case study training sessions for hospital staff and nurses (e.g., hostile family, same-sex parents at registration, youth with same gender partner, etc.).
  - e. Help clinical staff address implicit biases.

# **Patient Services & Support**

The Patient Services & Support criteria focuses on a wide variety of best practice recommendations from The Joint Commission and other sources to enhance care for LGBTQ patients. Four subsections compose this criteria, all of which have implications for children's hospitals:

- 1. LGBTQ Patient Services & Support;
- 2. Transgender Services & Support;
- 3. Patient Self-Identification; and
- 4. Medical Decision-making.

#### **Discussion**

Unlike adult hospitals where patients have autonomous decision-making capacity, participants reported that children's hospitals have the added challenge of incorporating the minor patient's needs and requests as part of clinical care and medical decision-making, along with the adult guardians' input.

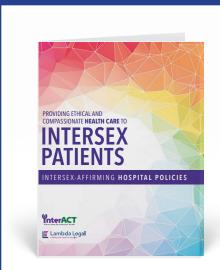
#### **LGBTQ Patient Services & Support**

Focus group participants discussed more challenges than successes in the area of developing and sustaining LGBTQ patient services and support. Some participants mentioned that their organizations placed the focus of care on gender identity issues and having a gender clinic, while other clinical issues related to sexuality and sexual orientation were left in the background and remained unaddressed.

Focus group participants discussed a number of challenges faced at their institutions when starting, developing and continuing services and support for LGBTQ patients. Participants reported challenges with system-level barriers, scheduling and instituting staff training and education, and obtaining sexual orientation and gender identity data for programmatic development. Existing processes were described as "messy, non-standard, and piecemealed," and participants noted the need for overarching policies addressing the care and support of LGBTQ patients, families and visitors.

Participants also recognized that some health systems hold convictions that the inclusion of LGBTQ concerns is in conflict with their organization's mission or values. Therefore, those mission-driven organizations can be resistant to change. Focus group participants reflected that change often has been driven forward as a result of patient and family dissatisfaction with being misgendered, often in the form of a formal complaint to the hospital's office of Patient Satisfaction or Ombudsperson.

In addition to the general challenges of serving LGBTQ patients, focus group participants also identified issues that were unique to children's hospitals. Participants discussed issues around sexual trafficking of LGBTQ youth and brainstormed various suggestions to help with this problem, including: improving training opportunities for Emergency Department providers on human trafficking and LGBTQ youth; developing collaborations with Sexual Assult Nurse Examiners (SANE); raising awareness on human trafficking with signs and banners; and establishing an outreach van service to connect with homeless and at-risk street youth.



#### INTERSEX-AFFIRMING HOSPITAL POLICIES

INTERSEX IS AN umbrella term that refers to the approximately 0.5 to 1.7% of the population born with variations in sex characteristics such as chromosomes, gonads, and/or genitals that vary from what is considered typical. Like non-intersex people, an intersex person may identify as transgender and/or non-binary if their gender differs from their assignment at birth. Intersex people may also identify anywhere along the sexual orientation spectrum, including as lesbian, gay, bisexual, queer or asexual.

Though more extensive discussion of intersex variations is outside the scope of this report, many intersex youth receive care at children's hospitals and can benefit from HEI policy standards. In addition, children's hospitals are encouraged to review the guide Providing Ethical and Compassionate Health Care to Intersex Patients: Intersex Affirming Hospital Policies written by inter-ACT: Advocates for Intersex Youth, Lambda Legal, and Proskauer Rose LLP. This guide offers concrete steps for medical providers to provide sensitive, non-discriminatory care to intersex patients, including recommended policies regarding the provision of affirming care to prevent liability and ensure patient-centered decision-making by avoiding non-consensual interventions that can be safely delayed until the patients are old enough to participate in the decision.

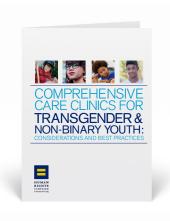
Participants raised additional challenges related to the behaviors and attitudes of the providers at children's hospitals. Pediatricians and hospital systems were described as being "in denial of adolescents as sexual beings and are uncomfortable addressing sex." Participants noted that developing programs promoting healthy sexuality was difficult, resulting in important gaps in care. Moreover, participants noted that sexual behaviors were routinely policed and shamed in the hospital setting, discouraging youth from discussing their sexual health needs or emerging sexual feelings. One participant described the tricky balance that children's hospitals faced between affirming and regulating their patients' sexual behaviors: "Children's hospitals toe the line between making patients and families with chronic health conditions feel welcome and at home while still having rules and behavior regulations."

Despite the many challenges faced in improving LGBTQ patient services and support, participants did report some successes. One participant shared their successful efforts with starting a safe space sign campaign at their children's hospital. After a provider was told not to wear a safe space sticker from another facility, it actually led to a movement within the hospital to create their own branded safe space stickers and LGBTQ logos which were placed throughout the hospital as a sign of inclusion.

# **Transgender Services & Support**

As noted earlier, many children's hospitals have focused their LGBTQ efforts on the creation of comprehensive multidisciplinary gender clinics. The number of these clinics has increased quickly over the past few years and several focus group participants represented children's hospitals that had multidisciplinary gender clinics. Children's hospitals that are interested in creating such a clinic are encouraged to review the guide *Comprehensive Care Clinics for Transgender and Non-Binary Youth: Considerations and Best Practices*.

Children's hospitals that have developed gender clinics have seen demand grow significantly, often quickly outpacing their capacity. While these programs have been incredibly successful, many children's hospitals have faced challenges serving their transgender patients.



# **Related Reports**

For information about creating a multidisciplinary gender clinic, see the publication, **Comprehensive Care Clinics for Transgender and Non-Binary Youth: Considerations and Best Practices**, from HRC Foundation.

This publication is available for download at: hrc.im/ComprehensiveCareClinics



For medical, mental health and education expert opinions on why gender-affirming care is the right and necessary approach, see the publication, **Supporting & Caring for Transgender Children**, from HRC Foundation, the American Academy of Pediatrics (AAP), and the American College of Osteopathic Pediatricians (ACOP).

This publication is available for download at: hrc.im/supportingtranschildren



For more information about best practices for care of transgender patients, see the publication, *Creating Equal Access to Quality Health Care for Transgender Patients: Transgender-Affirming Hospital Policies*, from HRC Foundation, Lambda Legal, and the LGBT Rights Committee of the New York City Bar Association.

This publication is available for download at: hrc.org/transgender-affirming-hospital-policies Like adult hospitals, many children's hospitals did not have policies in place regarding rooming gender expansive, non-binary and transgender patients. Most of the focus group participants shared that their institutions tried to find and justify single occupancy for transgender patients whenever possible. Patients were generally not upset, nor did they feel singled-out, by having a single-room assignment.

A specific clinical concern raised by participants was related to fertility preservation services for transgender youth planning for hormonal therapy. Focus group participants called for more resources such as ethics consults and specialists familiar with fertility preservation to be involved in these youth's care. They also stressed the importance of insurance coverage for these services to make them accessible and affordable.

Participants also noted that, like in other health settings, health professionals in gender clinics may interact with a hostile parent or family member. This may be the case when parents or guardians are not in agreement with the plan of care for a gender non-binary or transgender patient. Like other scenarios with the potential for violence, de-escalation strategies discussed included separating the parents; having social work or nursing engage the hostile parent to witness/document the situation; maintaining a safe emotional and physical environment for patients, staff and family members; and recruiting plain clothes police for safety.

Finally, participants noted that clinics and hospitals that provide services for transgender youth can find themselves the center of negative publicity on websites or social media, typically as a result of parents and guardians who disagree with their child's recommended plan of care. In some instances, healthcare professionals and clinics have received threats of violence. Participants agreed that working with the hospital's legal counsel, police force and administration is critical to address these negative interactions and potential threats to the safety of patients and employees.

Despite the many challenges, several participants noted successes in transgender services and support at their hospitals. One participant representing a children's hospital with a gender clinic shared their work in developing a comprehensive model transgender patient care policy which addressed many of the challenges raised by the group. Another participant shared their success with starting a pronoun sticker/pin awareness campaign to advocate for transgender patients and raise awareness of the importance of gender identity in the clinical setting.

#### **Patient Self-Identification**

One of the most common forms of discrimination that transgender people face is known as misgendering. This is when a person is referred to in a way that does not correctly reflect the gender with which they identify. Misgendering patients is not solely the result of human behavior; participants recognized the pivotal role that the electronic health records (EHR) can play in either facilitating the use of the patient's name and pronoun they go by, or reinforcing the use of the patient's legal name and pronouns associated with their sex assigned at birth. Though some EHRs have capacity for collecting and entering sexual orientation and gender identity data, not all hospitals are using those platforms.

Patient/family disclosure of sexual orientation and gender identity status is an important way for hospital systems to become aware of the needs of their sexual and gender minority clients. However, focus group participants shared that collecting sexual orientation and gender identity

data and obtaining consent to do so can be problematic in the children's hospital setting. This may occur when the parent/child dyad is not in sync with how data should be recorded in the EHR. Another challenge is related to the designated agent in the clinical setting who is trained and capable to enter that data. The job class of the staff member who can obtain this data, enter it and/or make changes was not uniform across the health systems represented by focus group participants. Depending on how this workflow was assigned, hospitals and clinics reported variable success with collecting and updating sexual orientation and gender identity data in the EHR. In addition to these systemic challenges, participants noted that it is important for patients, parents and families to assess their comfort level with being "out" to a healthcare system via the EHR.

One last barrier to collecting sexual orientation and gender identity data lies in the problem of EHR interoperability. There is a lack of effective communication of information among EHRs to collect both demographic and clinical data. As a result, sexual orientation and gender identity data is not necessarily shared between EHRs as patients receive health care from more than one health system.

Despite the challenges in patient self-identification, participants shared some achievements in standardizing the registration process at their hospitals. One participant discussed how their organization had trained staff and adjusted registration processes so demographic data (e.g., patient's legal name, insurance status) was obtained separately from the clinical interview where family structure was defined.

#### Recommendations

Focus group participants offered the following suggestions for children's hospitals to consider as they create policies and practices which address LGBTQ patient services and support:

- 1. Adopt policies and practices to create a welcoming environment for transgender patients.
- 2. Capture sexual orientation and gender identity data in electronic health records and train staff on how to capture this information in sensitive ways.
- 3. Develop more overarching wellness services with LGBTQ care embedded as part of the care plan.
- 4. Develop better referrals for contraception care, abortion and Pre-Exposure Prophylaxis (PrEP) care, especially for LGBTQ youth.
- 5. Consider developing an LGBTQ or transgender health navigator program.
- 6. Develop better plans to transition patients from pediatric/adolescent medicine based services to adult services, including those in LGBTQ health care.
- 7. Develop more inclusive fertility preservation care options for transgender youth.
- 8. Share more best practice patient care and communication tools such as "coming out letters" that patients use, social media videos, etc.
- 9. Utilize a variety of LGBTQ resources, including those developed by the HRC Foundation, PFLAG and the Family Acceptance Project.
- 10. Develop interventions to screen for sex trafficking of youth, including LGBTQ youth.
- 11. Develop mechanisms to address and prepare for negative social media and potential negative interactions in the clinical setting.





# **Employee Benefits & Policies**

The Employee Benefits & Policies criteria focuses on a wide variety of best practice recommendations from The Joint Commission and other sources to promote equity and inclusion for LGBTQ employees. A healthcare organization's LGBTQ employees play a vital role in ensuring LGBTQ patient-centered care by informally educating their co-workers about patient concerns, offering feedback about organizational policies and practices, and conveying to the local community their organization's commitment to equity and inclusion. It is critical that LGBTQ employees, like LGBTQ patients, receive equal treatment, particularly vis-à-vis health-related benefits and policies.

# **Discussion**

Participants reported that LGBTQ employee policy and benefits in children's hospitals followed their counterparts in adult hospitals; they did not feel that there were significant special considerations for children's hospitals.

Focus group participants shared that several of their institutions had established policies to enhance LGBTQ employee recruitment, retention and create an affirming work environments. One participant discussed how their organization included an LGBTQ employee resource group (ERG) as part of general recruitment efforts at community job fairs to demonstrate their hospital's commitment to inclusion and diversity.

Despite successes with developing inclusive processes and policies in hiring diverse employees, focus group participants also agreed that in general they struggled to have visible representation of LGBTQ faculty and staff. Some hospitals had LGBTQ-identified clinical or administrative leaders, but most institutions did not have such out, visible leaders in their ranks.

An additional challenge discussed was that of supporting faculty and staff who come out or transition on the job. As more and more companies are providing health benefits for transgender employees, more individuals may begin to transition while on the job. The 2019 HEI reported that 75% of participating healthcare facilities offered transgender-inclusive health benefits, up from 47% in 2017.10

Coming out or transitioning in a hospital environment may be more challenging for those who interact with youth or children. Focus group participants discussed the case of an academic pediatrician who underwent transition and gender affirmation treatment in the pediatric setting. Participants reflected on the unique developmentally appropriate conversations that she had with pediatric and adolescent patients and their families as she transitioned. An example of such a conversation addressed the gradual change in the physician's appearance and hair length, and how she addressed this in the context of a routine patient visit.

#### Recommendations

Having a supportive, inclusive work environment for LGBTQ employees at children's hospitals is an important part of overall diversity and inclusion efforts. Focus group participants offered the following suggestions for children's hospitals to consider as they create policies and benefits for their employees:

1. Establishing employee non-discrimination policies which are inclusive of gender-expression, gender identity and sexual orientation, if not already in place.

- 2. Ensure that equal benefits are offered to employees, including offering healthcare coverage for domestic partners and providing transgender-inclusive insurance options.
- Encouraging faculty and staff who are LGBTQ-identified and Allies to be as visible at the hospital as they can.
- 4. Developing and supporting LGBTQ ERGs.
- 5. Establishing supportive policies for employees, managers and their co-workers around transitioning in the workplace.

# **Patient & Community Engagement**

The Patient & Community Engagement criteria focuses on a wide variety of best practice recommendations from The Joint Commission and other sources regarding LGBTQ-related community engagement.

#### Discussion

The majority of patient satisfaction surveys do not collect sexual orientation and gender identity demographics, making tracking the concerns and needs of LGBTQ patients more difficult. Some hospitals have begun to collect such data, but focus group participants agreed that children's hospitals in general are lagging in this form of data collection. Therefore, it is important for children's hospitals to find ways to engage with the local LGBTQ community to make sure they are hearing about their needs and concerns.

Focus group participants agreed that progress has been made in increasing the presence of LGBTQ people and LGBTQ topics in their hospitals, and their hospitals have become more known in the LGBTQ community. Focus group participants described how their hospitals increased their engagement with local LGBTQ communities through establishing a presence at community Pride events, transgender health conferences, and conducting hospital-sponsored transgender job fairs. One hospital has partnered with their local United Way and other community organizations to address LGBTQ issues for youth, while other hospitals and prominent providers in hospitals have spoken out (provided testimony, written letters of opposition, etc) when state legislators have proposed bills that negatively impact transgender youth.

#### Recommendations

Focus group participants offered the following suggestions for children's hospitals to demonstrate LGBTQ community engagement:

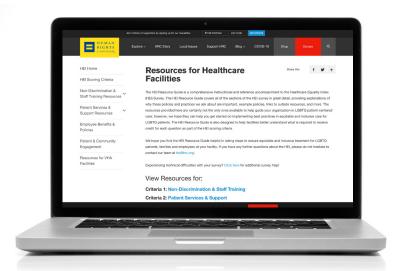
- 1. Collect LGBTQ status on patient care surveys to better understand the needs of patients and their families.
- 2. Being present and supporting LGBTQ community events and activities.
- 3. Inviting LGBTQ community members to be part of hospital advisory committees and boards to elevate their voices and concerns at the organization level.
- 4. Taking a public stand on state and federal legislation that impacts LGBTQ youth.

# **RESOURCES**



**The HEI Resource Guide** is a comprehensive instructional and reference accompaniment to the *HEI Survey*. The HEI Resource Guide covers each section of the HEI survey in great detail, providing explanations of why the policies and practices asked about are important, example policies, links to outside resources, and more. The resources provided in the guide are certainly not the only ones available to help guide facilities in LGBTQ patient-centered care; however, we hope they can help facilities get started on implementing best practices in equitable and inclusive care for LGBTQ patients. The HEI Resource Guide is also designed to help facilities better understand what is required to receive credit for each question as part of the HEI scoring criteria.

The HEI Resource Guide can be found at hrc.org/hei/resource-guide



In addition, you will find sample policies and **resources specifically for children's hospitals** on this page: hrc.im/ChildrensHospitals

#### **ENDNOTES**

- Kann L, McManus T, Harris WA, et al. Youth Risk Behavior Surveillance

  United States, 2017. MMWR Surveill Summ 2018;67(No. SS8):1–114. DOI: http://dx.doi.org/10.15585/mmwr.ss6708a1
  - Johns MM, Lowry R, Andrzejewski J, et al. Transgender Identity and Experiences of Violence Victimization, Substance Use, Suicide Risk, and Sexual Risk Behaviors Among High School Students 19 States and Large Urban School Districts, 2017. MMWR Morb Mortal Wkly Rep 2019;68:67–71. DOI: <a href="http://dx.doi.org/10.15585/mmwr.mm6803a3external.icon">http://dx.doi.org/10.15585/mmwr.mm6803a3external.icon</a>
- <sup>2</sup> HRC Foundation's internal analyses of YRBS data follow the guidelines set forth by the Centers for Disease Control. This includes properly weighting. The analysis uses the primary sampling unit and strata variables provided by CDC to estimate standard errors correctly. Strata with a single unit are centered at the population mean.
- 3 Ibio
- 4 Kahn, E, et al (2018). 2018 LGBTQ Youth Report. Human Rights Campaign Foundation.
- Gates, G. J. (2015). Marriage and Family: LGBT Individuals and Samesex Couples. *The Future of Children*, 25(2), 67-87. Retrieved from <a href="https://escholarship.org/uc/item/2gn0m81f">https://escholarship.org/uc/item/2gn0m81f</a>
- General Social Survey. <a href="https://gss.norc.org/">https://gss.norc.org/</a> Accessed March 2, 2020.
- Stahl RY, Emanuel EJ. Physicians, Not Conscripts Conscientious Objection in Health Care. N Engl J Med. 2017 Apr 6;376(14):1380-1385. doi: 10.1056/NEJMsb1612472. No abstract available. PMID: 28379789
- Sabin JA, Riskind RG, Nosek BA, "Health Care Providers' Implicit and Explicit Attitudes Toward Lesbian Women and Gay Men", *American Journal of Public Health* 105, no. 9 (September 1, 2015): pp. 1831-1841. DOI: 10.2105/AJPH.2015.302631 PMID: 26180976
- An intersectional lens focuses on the intersections of multiple, mutually-reinforcing systems of power, oppression and privilege. We all have multiple identities (some visible and some invisible) that intersect to make us who we are—our race, ethnicity, sexual orientation, gender identity, socio-economic status, religion, ability, education, etc.
- 10 2019 Healthcare Equality Index. Human Rights Campaign. <a href="https://www.hrc.org/hei">https://www.hrc.org/hei</a>



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