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Chapter

From Margins to Mainstream: Creating a Rural-Based Center of Excellence in Transgender Health for Upstate, New York

Carolyn Wolf-Gould

Abstract

Transgender people face many barriers to healthcare, especially in rural America. The work to decrease barriers to care and address health care disparities for this population meets criteria for a *wicked problem,* each of which is unique and has no clear solution. The barriers are related to the individual and society and are both formal and informal. The definition for a Center of Excellence in healthcare is loose, but these organizations aspire to serve as specialized programs that offer comprehensive, interdisciplinary expertise and resources within a medical field to improve patient outcomes. With funding and leadership training from the Robert Wood Johnson Clinical Scholars program, a group of medical and mental health clinicians worked for three years with the goal of creating a Rural-Based Center of Excellence in Transgender Health embedded within a family practice to approach the wicked problem of transgender healthcare in their region. The goals of the center were six pronged: the provision of competent and affirming medical, surgical and mental health services, training for healthcare professional students, medical-legal advocacy and patient-centered research. The team created a strategic plan, with five strategic directions, including 1) developing infrastructure and organizational capacity, 2) expanding awareness, knowledge and skills, 3) fulfilling staffing needs, 4) ensuring gender-affirming care, and 5) advancing evidence-based care. I describe our work to bring transgender health from the margins to the mainstream for our region through implementation of this strategic plan.

Keywords: Transgender Health, Center of Excellence, Healthcare Disparities, Rural Healthcare, Barriers to Care, Wicked Problem

1. Introduction

Transgender and gender-nonconforming people face relentless discrimination in employment, family life, education, housing, faith-based settings, and public accommodation, but some of the most appalling discrimination occurs in healthcare settings, when individuals reach out for help [1]. Transgender people are among the most marginalized in our nation and that marginalization extends to healthcare.

A recent survey of transgender people shows minimal improvement in access to affirming healthcare between 2011 and 2015, and many continue to face

insurmountable barriers [1, 2]. Of those recently surveyed, 25% reported experiencing a problem with their insurance in the past year related to being transgender; 33% who saw a healthcare clinician reported at least one negative experience related to being transgender; 55% of those who sought coverage for transition-related surgery were denied; and 23% of respondents did not see a doctor when they needed to, due to fear of maltreatment [2].

Barriers to healthcare, visualized in **Figure 1**, include problems related to the *individual* and *society* and are both *formal* and *informal*. *Individual/informal* barriers to care include self-stigma and minority stress, which negatively impact the ability of transgender people to reach out for care. Minority stress refers to the protracted level of stress faced by members of stigmatized, minority populations, leading to the internalization of negative societal mores, shame, or fear of personal harm [3, 4]. This may result in self-stigma, leading to denial or concealment of one's identity in medical settings. *Individual/formal* barriers to care include the absence of affirming services for transgender people, due to the lack of medical training, clinician ignorance and/or implicit bias and transphobia [5–8]. The result is clinician discomfort that is reflected, intentionally or unintentionally, onto transgender patients who, when asking for help, are met instead with confusion, curiosity, hostility and incompetence.

Formal/Institutional barriers to care, in turn, include structural stigma resulting from the lack of protections that ensure a right to affirming care; the problem of structural stigma is further associated with higher mortality in sexual and gender minorities [9]. Causes of structural stigma include the dearth of governmental policy protections; the lack of insurance coverage for transition related care; the exclusion of gender identity/gender expression in antidiscrimination policies; the absence of institutional trainings on cultural responsiveness; and the failure to employ electronic medical records (EMR) to capture the nuanced experience and demographics of gender diverse people [10, 11].

Finally, *societal/informal* stigma, in the form of rejection, abuse, and discrimination, leads to increased rates of depression, suicidality, violence, substance abuse, HIV, unemployment and homelessness, all conditions that impede an individual's ability to access and follow through with healthcare [12–19].

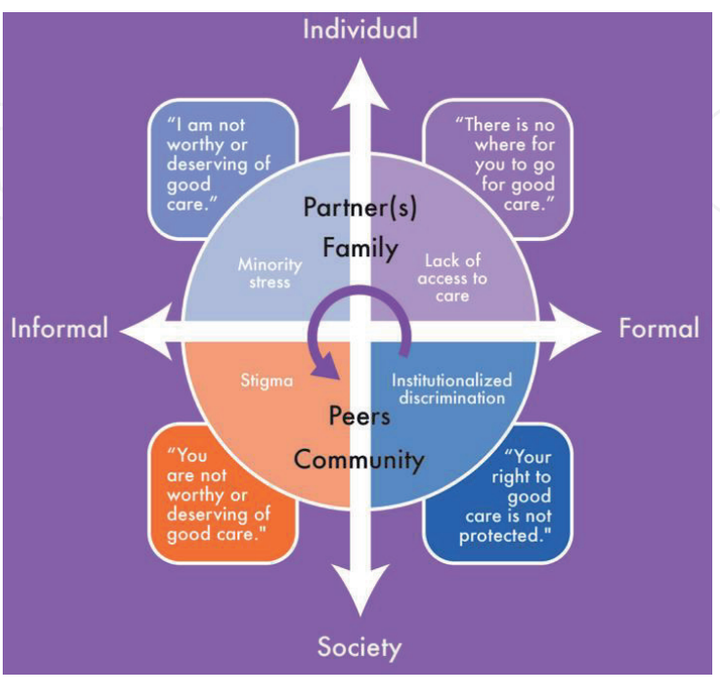


Figure 1.
Barriers to care for transgender patients.

These barriers to care are linked and strengthened by a circular, self-perpetuating energy. The result? Most transgender people face inordinate stress while attempting access to healthcare. Many delay care, presenting only to emergency rooms, in extremis. Others forgo all healthcare, ignore illness, and self-treat their gender dysphoria with unregulated hormones purchased on the internet. Others fear coming out and requesting help from clinicians, presenting instead with a bewildering array of symptoms and behaviors related to minority stress/dysphoria that are not disclosed, acknowledged or addressed. The effects of the resultant healthcare disparities ripple into the wider world where the suffering of transgender people is translated into devastating and expensive societal problems. Individuals, families, peers, healthcare institutions, and communities are all damaged by the costs of poor care.

Place of residency/environmental circumstance is a critical social determinant of health and significant research gaps exist around the experience and needs of rural transgender populations. Limited studies suggest that rural transgender people experience additional barriers to healthcare, including decreased access to trans-competent medical and mental health professionals, social isolation, transportation issues, financial constraints, and concerns about confidentiality [20, 21]. They have less political power, increased visibility, fewer alternatives in the face of discrimination, fewer support structures, and less support from faith organizations and local government [22]. Rural LGBTQ people devote more time to travel for healthcare, a factor associated with higher rates of depression and anxiety [23]. Higher scores on stigma scales for rural transgender people is associated with lower utilization of healthcare services [24]. Rural transgender people express higher Brief Symptom Inventory Somatization Scales, higher rates of depression, unprotected sex and decreased self-esteem compared to their urban counterparts [25]. Rural transgender veterans show increased rates of tobacco use and PTSD compared to urban peers [26]. The ability of transgender men to integrate in a rural environment is limited to those who are not out and who conform to "sameness," "whiteness and enacting appropriate rural working-class heterosexual masculinities" [27].

Population and student surveys estimate the incidence of transgenderism at 0.5% to 2.7% [28, 29]. Over the last few years, the visibility of transgender people across the nation has reached a tipping point, leading to an increase in the numbers of people seeking healthcare and the demand on healthcare facilities to respond to this need [30, 31].

In urban centers, specialized clinics may exist to provide LGBTQ affirming healthcare services, but clinicians in rural areas lack a replicable model for healthcare delivery. In the Northeast United States, clinics offering gender-affirming care are usually urban, federally qualified health centers [32–34]. These centers are designed to address identified healthcare disparities for LGBTQ individuals in communities with high need. They advertise well, offer a sense of community and expertise regarding LGBTQ health, and hire staff who represent and are committed to serving this population. In rural areas, most LGBTQ people receive services in primary care offices from clinicians who offer LGBTQ specific services from within a general practice [35]. This embedded model for care provides anonymity to patients who prefer not to self-identify. However, these settings may be staffed by clinicians with limited training in LGBTQ health who have a narrow scope of practice and cannot provide services for social support and education.

The complex, interdisciplinary nature of transgender healthcare and the inability of most medical systems to offer competent trans-specific and gender-affirming healthcare meets criteria for a *wicked problem* [36]. Wicked problems are systemic, malignant, persistent and inflict incalculable pain and suffering onto individuals and communities. By definition, a wicked problem is one "for which each attempt

to create a solution changes the understanding of the problem" [36]. The usual linear approach to problem solving with planning and implementation only creates additional work. Every small solution to a piece of the puzzle leads to an entirely new set of wicked problems, each with its own muddy set of expensive consequences, requiring urgent and consuming attention. The larger problem is "ill structured, an evolving set of interlocking issues and constraints" [37]. Each wicked problem is unique and has no clear solution. Efforts to solve them must use novel approaches that are hard to measure, rarely finished, and usually limited by dwindling resources.

To address the wicked problem of transgender healthcare, clinicians and staff may take deliberate steps to create welcoming environments for transgender patients by constructing appropriate visual cues, providing cultural responsiveness training, capturing appropriate demographic information, updating policies and procedures, and mastering clinical skills [35, 38]. But most clinicians and staff have neither the interest, time, nor resources for these tasks and require organizational mandates and support. Effecting organizational change to create welcoming clinic/hospital networks is a larger wicked problem, requiring institutional leadership to recognize the barriers to care, perform honest assessments, and commit to cultural change.

One organizational change model to promote inclusion and reduce disparities for LGBTQ people identifies a need for both *elements* (organizational resources) and *processes* (dynamic strategies) to effect change [39]. Six *elements* identified as critical for success are: organizational champions, organizational priority, depth of mission, commitment to continuous learning, commitment to diversity and inclusion, and organizational resources. The six *processes* required for success include: management of change, information exchange, action research, relationship building, putting values into action, and leveraging resources. While effecting organizational change requires a daunting multi-dimensional transformation within the entire Culture of Health, this process is often sparked when one person recognizes the barriers to care for an individual patient.

Rural and urban healthcare systems develop Centers of Excellence (COE) to tackle the complex needs of specific populations. These organizations aspire to serve as specialized programs that offer comprehensive, interdisciplinary care and resources within a medical field to improve patient outcomes [40]. COEs are developed to create cultures that put patients first and keep people healthier and out of the hospital [41]. Clinicians in COEs provide leadership, demonstrate best practices, measure quality, conduct research, and offer support and training for a focus area. However, no strict criteria exist for programs to achieve the designation of a COE, and institutions demonstrate uneven success in ensuring that the term is used to reflect quality, rather than used as a marketing ploy [42]. Institutions have started creating quality-based Centers of Excellence to address the wicked problem of transgender health in a few urban settings, but not in rural healthcare institutions [43, 44].

This chapter describes how clinicians within a family practice addressed the wicked problem of access to healthcare for their region by working toward the creation of a Rural-Based Center of Excellence in Transgender Health. This story began with a request for care from a transgender patient in 2007 to the author, a family physician with no experience in the field. Using the embedded model for care, the practice has evolved and in 2019, exists as an interdisciplinary center that has provided medical, surgical, and mental health services to over 1000 transgender patients and their families. This paper describes our journey. It is our hope that our embedded care model will be replicated in rural-based primary care clinics across the nation, ensuring that transgender healthcare is brought from margins to mainstream medical practice in the United States.

2. Wicked problem impact project (WPIP) description

The creation of the rural-based Gender Wellness Center (GWC) began in 2007, when a transgender man asked the author to provide continuation of his testosterone therapy. Uncertain of how to proceed but unwilling to turn the patient away, she agreed to self-train to manage the patient's hormone regimen. Over time, more patients presented for care, necessitating the addition of additional services. A clinical social worker began providing mental health services and local surgeons began providing some basic gender-affirming surgeries (chest reconstruction, breast augmentation, hysterectomy and orchiectomy). In December 2014, Governor Andrew Cuomo mandated that all New York State public and private insurance cover medical and surgical treatment for transgender patients which in turn led to a sharp uptick in patient volume at our clinic. In 2015, to recognize this development in specialized care, we established the GWC as part of the family practice by hanging a new office sign for The Gender Wellness Center/Susquehanna Family Practice and creating a website (www.genderwellnesscenter.com).

By 2016, over 350 transgender patients had received services at the GWC and problems around the delivery of care began to surface. Due to complex

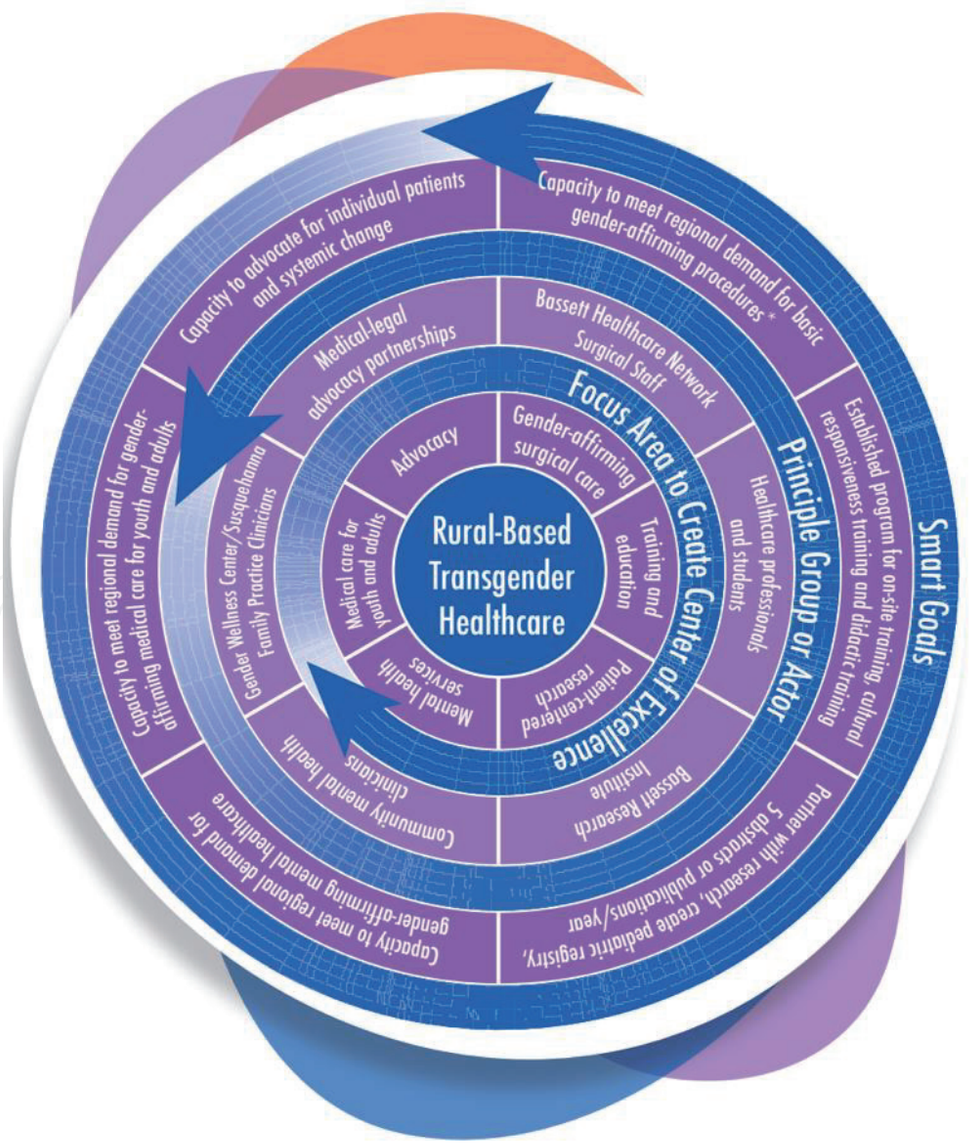


Figure 2.
The wicked wheel: creating a rural-based center of excellence for transgender health.

biopsychosocial needs, the patients often required extra time and support from staff and clinicians, including the provision of medical-legal advocacy, staff training, and coordination of care with interdisciplinary services, community-based organizations, schools and employers. Though proud of the quality of services offered, we were aware that the GWC had been hastily cobbled together to meet the immediate needs of desperate patients and lacked institutional support and a sustainable organizational structure. Although the hospital administration had offered tentative support, they had not helped to identify and address the changing needs of the practice and, like all rural hospitals in upstate New York, faced financial challenges and a multitude of competing priorities. Many of the patients required complex care coordination with service organizations and specialists who lacked basic education about transgender people. A transgender man was denied hysterectomy at a network hospital due to gender identity issues, indicating a critical need for organizational education.

In 2016, as the author began looking for funding to expand and improve services, she assembled an interdisciplinary team (two family practice physicians, an OB/GYN surgeon, and a clinical social worker) to meet the complex medical, mental health and surgical needs of this population. The team applied for and was awarded a Robert Wood Johnson Foundation (RWJF) Clinical Scholars Grant to explore the possibility of creating a Center of Excellence in transgender health for the Bassett Healthcare Network.

The focus in creating a COE was six pronged, and included specific goals around 1) the provision of gender-affirming healthcare for transgender and gender nonconforming youth and adults, 2) the provision of gender-affirming mental health services, 3) the provision of gender-affirming surgical care, 4) effective medical-legal advocacy, 5) training and education, and 6) patient-centered research. **Figure 2** depicts the wicked problems around transgender healthcare and the team's six identified SMART goals.

3. Methods

The Gender Wellness Center (GWC) is embedded within Susquehanna Family Practice (SQFP), one of several primary care practices affiliated with A.O. Fox Hospital, a small community hospital in Oneonta, New York (**Figure 3**). A college town, with a population of 14,000, Oneonta is located within 1–2 hours of the urban centers of Albany, Syracuse and Binghamton. A.O [45]. Fox Hospital recently merged with The Bassett Healthcare Network (BHN), a collection of rural based hospitals and outpatient clinics serving a large swath of upstate, NY. In this chapter the "team" refers to the group of seven mental health, medical, nursing and surgical clinicians who worked closely together from within the GWC at SQFP on this project.

Our team's first step was to create a mission, vision, and values statement. We intentionally aligned our statement with the mission of our healthcare network, embracing the tenets of excellence in patient care, health research and healthcare education [46]. Additionally, our vision statement included the intent to "bring transgender healthcare from the margins to the mainstream" by creating a model for rural-based comprehensive care (**Figure 4**).

To advance exploration around creating a COE, our team met frequently with a research team from the Center for Evaluating Rural Interventions (CERI) at the Bassett Research Institute (BRI). CERI and the GWC clinicians conducted focus groups to assess community need and created logic models to explore project goals and the steps required to achieve them. Our team developed project evaluation tools, including Social Network Analysis, pre and post testing for trainings, and quality assurance chart audits, and a plan to create a pediatric patient registry.

DOI: http://dx.doi.org/10.5772/intechopen.98453

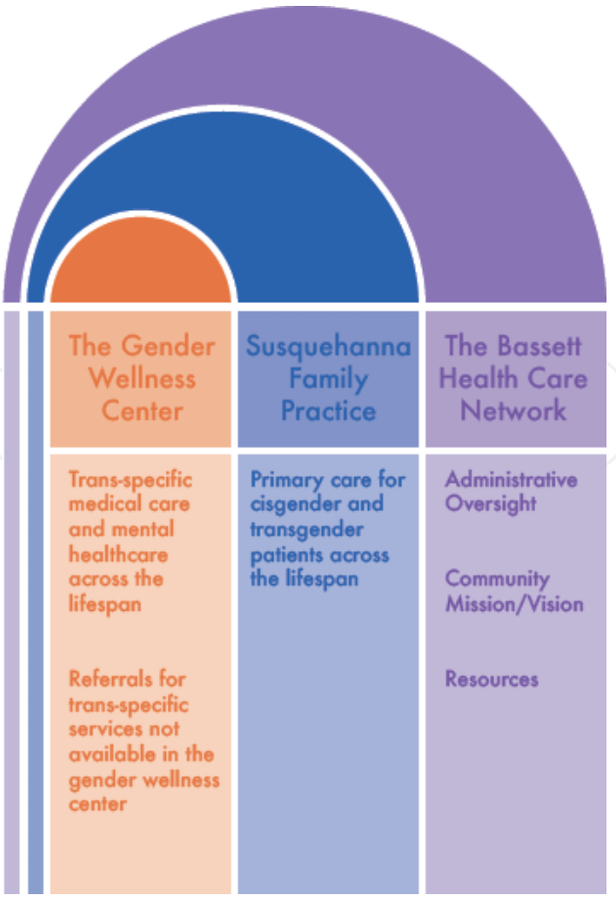


Figure 3.
The embedded model of care for the gender wellness center.



Figure 4.
The Mission, vision and values of the gender wellness center.



Figure 5.
The gender wellness center strategic plan: five strategic directions.

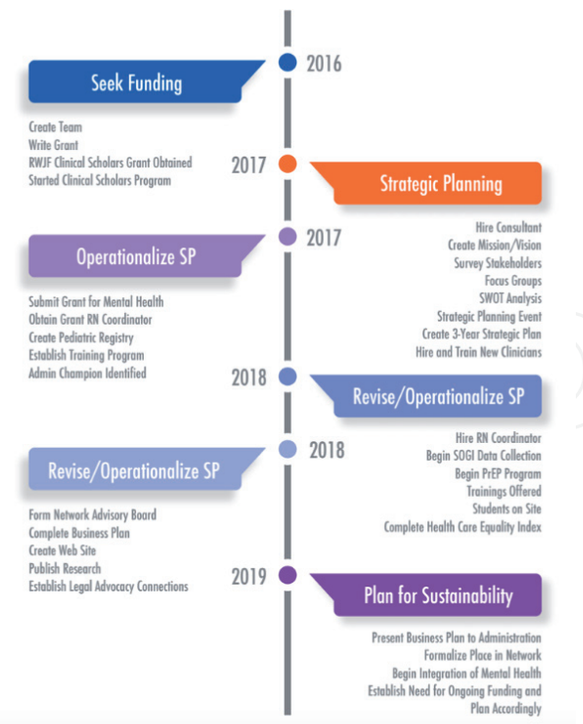


Figure 6.
Timeline for the gender wellness center strategic plan.

July 2017 saw the start of the strategic planning process. We conducted individual stakeholder interviews, a network/community survey, a student survey, and a patient satisfaction survey. In October 2017, stakeholders, including patients,

employees from regional Community Based Organizations (CBOs), network administrators, employees, and community members participated in two forums to review data from the surveys, and identify strengths, weaknesses, opportunities and threats to the evolving program. Our team then developed a 2-year strategic plan with five strategic directions, and specific goals for each direction. The five strategic directions included 1) Developing infrastructure and organizational capacity, 2) Expanding awareness, knowledge and skills, 3) Fulfilling staffing needs, 4) Ensuring gender-affirming care, and 5) Advancing evidence-based care (**Figure 5**). The plan was distributed to all stakeholders.

The remainder of the grant funding period was devoted to operationalizing the strategic plan. During this time, the team met quarterly to assign projects, review the status of projects, and then update the strategic plan, including identifying and addressing a number of specific projects and goals for each strategic initiative. We met weekly to discuss project implementation at a granular level by assessing, planning, executing, and evaluating. **Figure 6** depicts the timeline for project development and implementation.

4. Outcomes/results

The numbers of patients served at the GWC grew significantly during the three-year period of the RWJF Clinical Scholars program, as demonstrated in **Figure 7**. To date, we have served over 750 medical patients and 300 mental health patients. On average, patients travel 60 miles to be seen at the GWC but the catchment area for

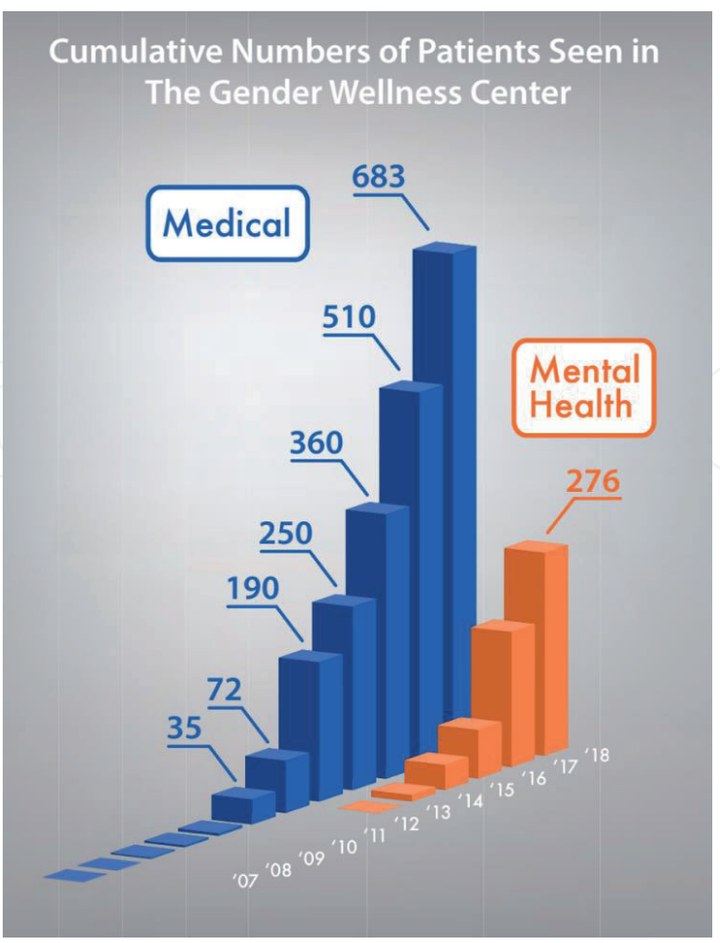


Figure 7.
Cumulative numbers of patients seen in the gender wellness center 2007–2018.

adults includes many counties across New York state as well as neighboring states [47]. **Figure 8** depicts the catchment area for GWC pediatric patients, as captured in the GWC Pediatric Registry with rural–urban distribution by zip code [48]. Transgender patients currently represent approximately 25% of the total number of patients seen at Susquehanna Family Practice [47].

4.1 Developing infrastructure and organizational capacity

Due to the interdisciplinary nature of transgender healthcare, our team identified the need to employ an interdisciplinary approach to organization and administrative oversight, in addition to patient care. To this end, we formed a Network Advisory Board (NAB) comprised of leaders in the network administration; members of the surgical, mental health and medical divisions; and transgender community members. This group served as a sounding board as our team developed and presented our business plan and explored a place for the GWC within the network organizational structure.

We also developed organizational structure within our office and A.O. Fox Hospital. We established monthly, peer protected, interdisciplinary rounds for case review and care coordination. We created quality measures, based on

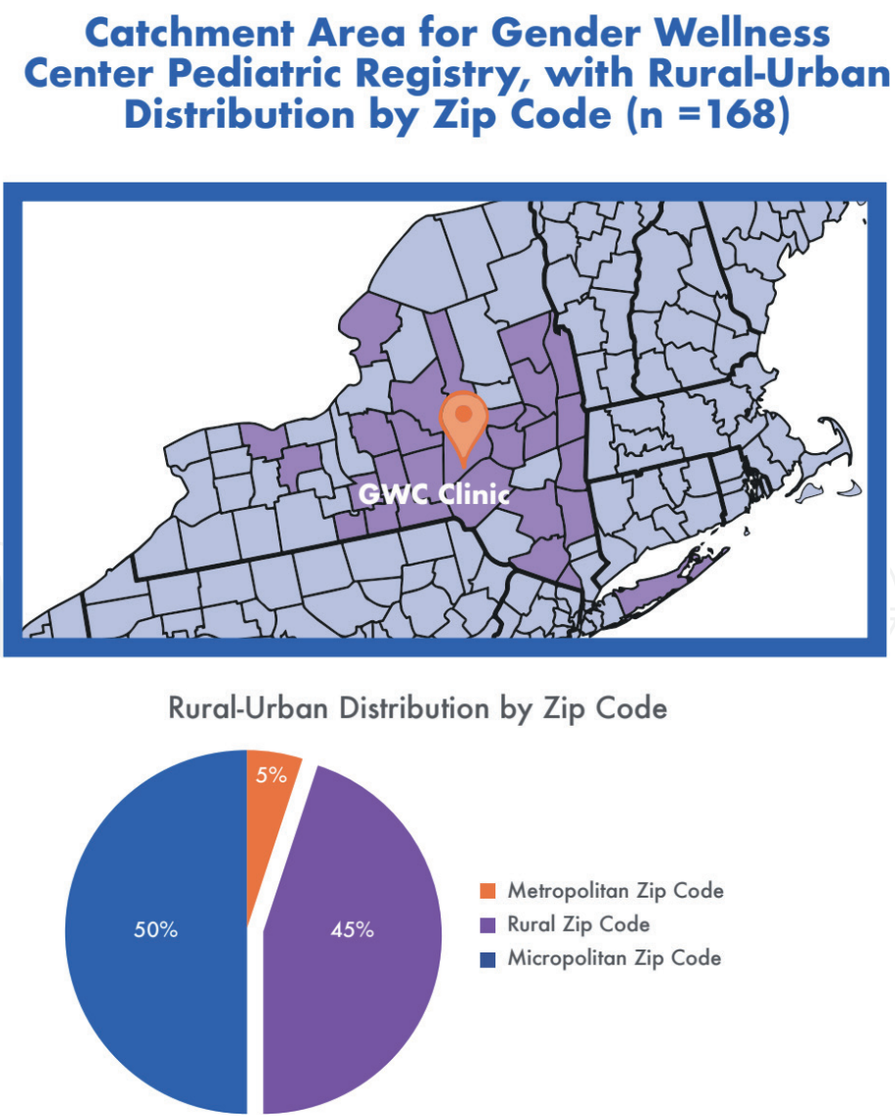


Figure 8.
Catchment area for gender wellness center pediatric registry.

recommendations from the World Professional Association's Standards of Care and Endocrine Society Clinical Practice Guidelines and performed quarterly chart audits [49, 50], and designed practices to ensure smooth entry to appropriate services within the GWC and referrals between disciplines.

Team members worked with A.O. Fox Hospital staff to achieve certification as a "Leader in LGBTQ Health" from the Healthcare Equality Index (HEI). This benchmarking tool, offered by the Human Rights Campaign, ensures LGBTQ affirming hospital policies, procedures and services [51].

Developing ties to a number of regional LGBTQ-affirming CBOs, including Planned Parenthood, the AIDS Institute, the NYS LGBTQ Network, community centers, counseling centers, government programs, and legal agencies, created partnership opportunities for meaningful connection to others doing similar work as well as important patient services.

4.2 Expanding awareness, knowledge and skills

The team identified the need to train ourselves, our staff, our network, healthcare professional students, and our wider community. Three of the clinicians served as coordinators for educational initiatives and all clinicians assisted with training. Several of our clinicians were new to transgender health and intentionally developed clinical skills through training and mentoring. Our office staff required cultural responsiveness training and forums to discuss ethical concerns around the care of trans youth. We developed onboarding procedures for new hires. We partnered with a professional trainer to offer trans-led cultural responsiveness education within the network and community. These trainings were filmed and will soon be included in orientation for all network hires. We offered didactic trainings at professional conferences, for specific organizations and via webinar. The physicians developed on-site clinical rotations to train professionals and students and established formal training connections with Yale and Columbia-Bassett Medical School.

4.3 Fulfilling staffing needs

To meet the growing demand for services, we recruited new clinicians and developed specialized roles within the team. Assigning job titles and creating job descriptions for team members contributed to the business plan (i.e. Director of Training, Coordinator for Surgical Services, Liaison to Research Team, etc.). The organizational chart is continually reviewed and adjusted as the COE evolves and there is ongoing discussion with network administrators about how to fit our chart within the larger network organizational structure.

We identified a senior network administrator to serve as our champion. Our team liaison met with him regularly to review plans and solicit advice. Our team met frequently with local and network administrators to address specific healthcare disparities faced by our patients and to advocate for improved services.

Our office was appointed an experienced office manager who ensured that staff were appropriately trained and monitored around the provision of culturally responsive care for all patients. We created a job description for the position of RN Coordinator for the GWC, which includes patient care coordination, project development, training and assisting with research, applied for funding and were awarded a two-year grant for this position.

As common in rural areas, we have struggled with limited access to adult and pediatric psychiatric care. In year two of our grant, the network hired a psychiatric clinician with an interest in transgender health. During his stay, we developed an effective collaborative process.

Our team identified the need to develop a sustainable model for mental health services as a key strategic initiative. Until 2019, our mental health clinicians worked with a private practice model and low sliding scale fee, a system that was not sustainable. In 2019, the New York State Department of Health awarded our team a 5-year grant to establish salaried positions for mental health clinicians within the BHN and offer mental health services for free.

We developed legal advocacy services through years of collaboration with regional CBOs who assist with problems around Medicaid law, insurance denials, discrimination, family law, and document changes, but patient need has continually exceeded capacity. We met with a community partner to assess need, envision a plan, and seek funding. This partner then also received a 5-year grant to develop formal medical-legal partnerships with the GWC and other regional transgender health providers.

The phrase "nothing about us without us" reflects the need for inclusive hiring to create welcoming communities. Our office included a transgender person to serve on our clinical team.

The need to ensure community participation in review of ethical concerns related to trans healthcare led our team to ask that a member of the transgender community be appointed to the hospital ethics committee. This request was readily adopted by our hospital administration.

4.4 Ensuring gender-affirming care

Placing visual cues, including welcoming signs, patient education materials, and notices about local LGBTQ services in the office waiting room, coupled with displaying our hospital's revised non-discrimination policy, which now includes gender identity/expression, became useful strategies. We designated all single stall restrooms in the office as gender neutral and updated forms to ensure inclusivity for diverse gender identities and family structures. All staff were trained in cultural responsiveness. We worked with our network public relations team to develop branding, update our website and develop an affirming marketing plan.

To ensure appropriate collection of demographic data, we worked with information technology from the BHN to include a collection tool for data on sexual orientation/gender identity (SOGI) in the EMR. The medical clinicians collect SOGI data on all patients in the family practice. A subsequent network-wide upgrade to our EMR and accompanying educational campaign soon ensures that SOGI data is collected in all clinical settings.

The medical clinicians sought training in the provision of Pre and Post-Exposure Prophylaxis for HIV (PrEP and PEP) and Medication Assisted Therapy (MAT) for the treatment of substance abuse so that these critical services can be accessed by all patient at the GWC/SQFP. Our team works closely with network surgeons who offer basic gender-affirming surgical services, including breast augmentation, chest reconstruction, orchiectomy, and hysterectomy. We developed educational materials and practices to assist patients with referrals for specialized gender surgery services not available in network and for postoperative care. Two of the GWC physicians volunteer at a community based free clinic in Oneonta to offer care to transgender people without insurance.

To advance evidence-based care, our team recreated a Community Research Advisory Team (CREATE) of transgender community members to assist us in ensuring that our research efforts are affirming and appropriate to community need. This group meets quarterly and has recently also begun to serve as a Community Advisory Board (CAB) to advise our team around the provision of affirming services.

4.5 Advancing evidence-based care

We developed close collaboration with members of the Bassett Research Institute with the goal of creating a patient registry and producing five publications/abstracts per year. This larger team created the first rural-based patient registry for gender-expansive pediatric patients in the country and we have begun publishing our data. Team members also contribute to the field with abstracts, case reports and book chapters [48, 52–60].

We identified a need to develop quality assessment measures. With the assistance of the A.O. Fox Quality Management Services, our team developed a tool for quarterly audit of medical charts, based on published care guidelines [49, 50]. We formed our Interdisciplinary Rounds based on these same published guidelines, a venue for peer protected, team review of complex cases and for youth receiving medical interventions [50].

5. Project evaluation

Our team employed seven different evaluation methods to track program implementation. Recording the cumulative growth of patients seen by medical



Figure 9.
Strategic plan implementation: direction and initiatives.

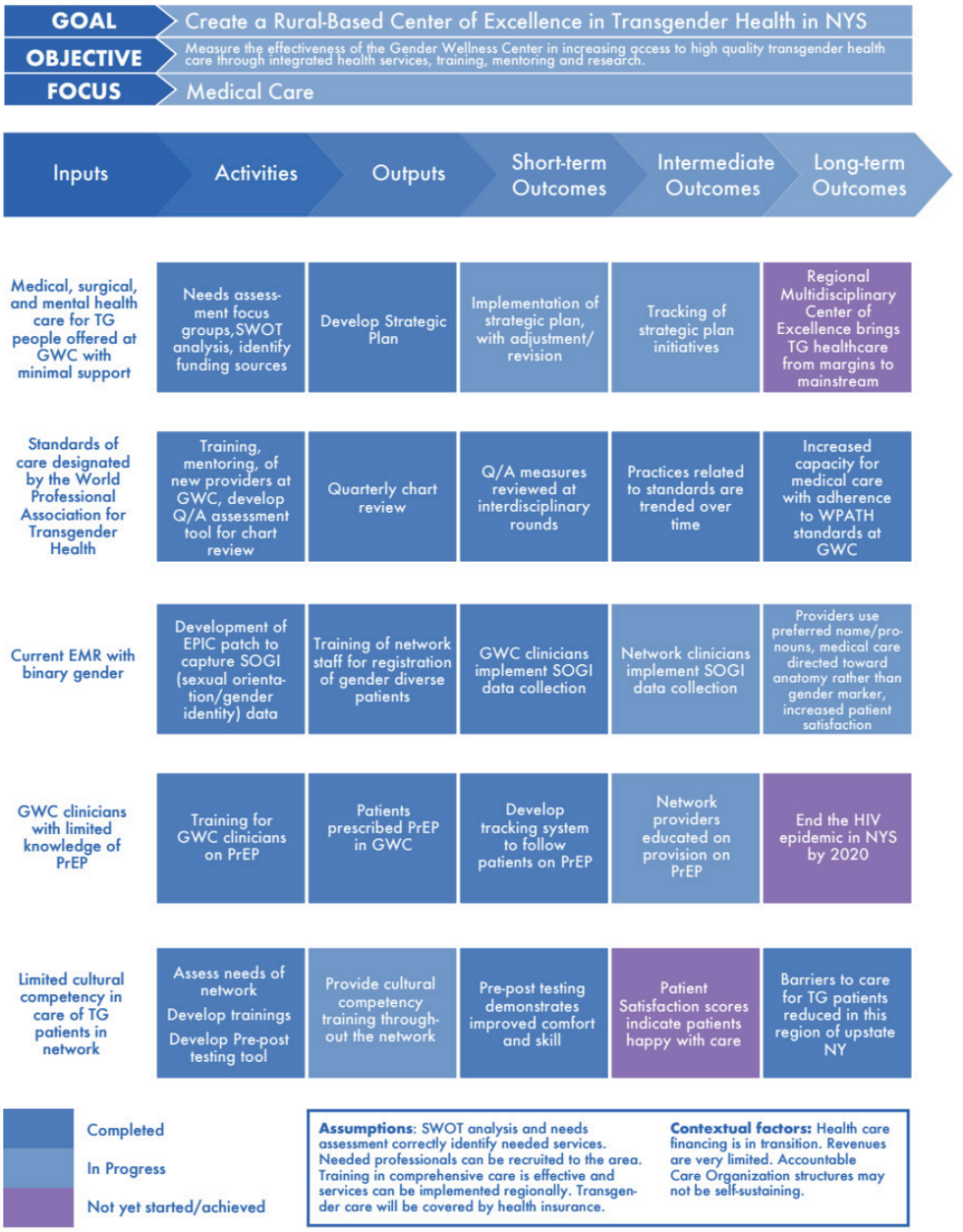


Figure 10.
Logic model: creating a center of excellence in transgender health.

and mental health clinicians was a process that started with the first patient in 2007 (**Figure 7**). We developed a chart to track strategic plan implementation (**Figure 9** depicts strategic directions and initiatives) and updated our logic models to demonstrate progression of projects over time (**Figure 10**). We recorded all publications, including abstracts, book chapters and articles and tracked didactic and on-site clinical trainings and obtained pre- and post- testing to illustrate how training "moved the needle" around staff/clinician comfort in the provision of care. We performed Social Network Analysis (SNA) to measure engagement and map the relationships of the GWC clinicians with others, locally and outside the BHN. **Figure 11** is the SNA map for a three-year grant period, demonstrating an increasingly denser network (more ties) with a rounder shape, (increasing connection within and external to the BHN) for our clinicians. It demonstrates improvements in networks/communications and cosmopolitanism over time. Our medical team reviewed all quarterly quality assurance reports with appropriate administrators

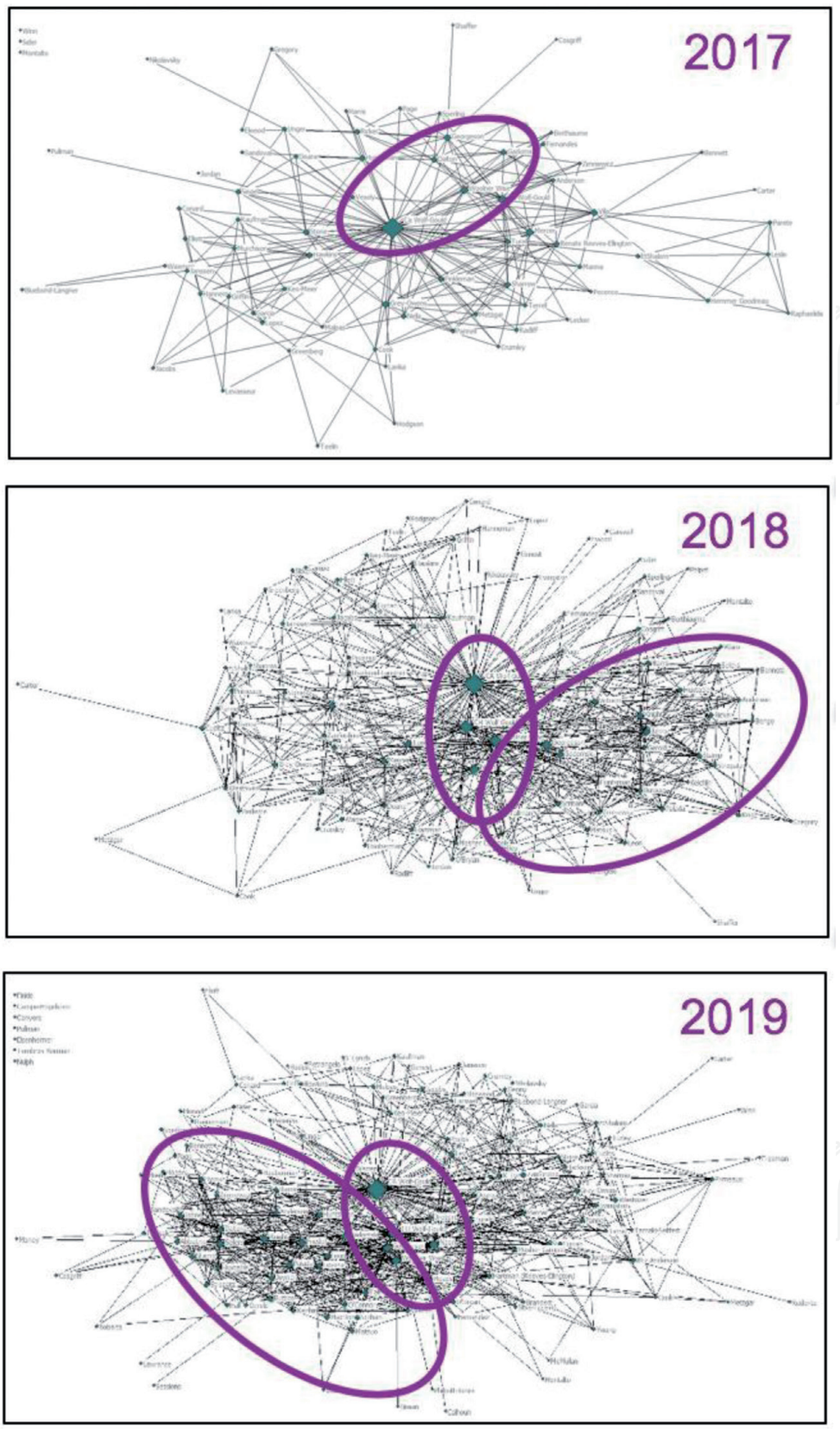


Figure 11.
SNA mapping to measure social capital and network formation.

within the BHN. We worked with the Bassett Research Institute to employ the Consolidated Framework for Implementation Research to evaluate project implementation (**Figure 12**) [61–63]. This system assesses results through a wide lens that includes the formative successes and limitations of project performance at various levels (i.e. level of patient, clinician team, organizational and market/policy level), within our specific setting, with our unique leadership, culture and team [64].



Figure 12.
Consolidated framework for implementation research.

6. Discussion

Approaching the conclusion of the RWJF Clinical Scholars grant period, our team reflected on the following: 1) Is the GWC a Center of Excellence yet? 2) What have been our biggest successes and challenges? 3) Have we moved transgender healthcare from the margins to mainstream? 4) How have we benefited from the leadership training of the Clinical Scholars program? 5) And, what legacy do we leave behind from our work?

Is the Gender Wellness Center a Center of Excellence yet? Loose definitions for COEs leave room for generous interpretation and tempt us to premature claims of success. As the first to attempt to create a Rural-Based COE in Transgender Health, we have had to draw our own road map and create our own measures for success. After discussion among our team members, we conclude that **we have not yet arrived**. This effort still lacks key components of sustainability, including a clear place in our network organizational structure, a plan for succession, adequate financial resources and assistance with project administration. Our team needs new clinicians, and an infusion of energy. We remain uncertain if the GWC will live beyond our new New York State Department of Health grant funding and the

careers of the current clinicians. We have seen that the process of 1) stating our intention and then 2) working toward the creation of a Center of Excellence has allowed us to employ both change *elements* (organizational resources) and *processes* (dynamic strategies) to promote inclusion and reduce health care disparities in our region [39]. But changing the Culture of Health is slow work. Although our team has not yet attained our goal of creating a Center of Excellence, we believe that we have created a **Center for Exceptional Care in Transgender Health (CFECTH).**

The nature of the *wicked problem* of transgender healthcare led to significant challenges around program implementation. Like all *wicked problems*, ours has evolved, not been solved. Every small solution to a piece of our puzzle has led to an entirely new set of *wicked problems*, requiring ongoing attention. While the logic model depicts an organized approach to problem identification and solving, **Figure 13**. more accurately reflects the chaos and complexity we experienced while addressing our *wicked problem*.

For example, as we devoted time and energy to addressing health care disparities for transgender patients, we were criticized by some hospital personnel and community members for "discriminating against cisgender patients." Staff turnover/resistance and the loss of some cisgender patients who objected our changing focus presented obstacles as well. We struggled to "change this narrative" through education on health equity and by continuing to provide primary care for cisgender patients (roughly 75% of total patient care). Other staff left because we were not progressive enough, the pay was too low, and the demands of the office too high. We are challenged by the fact that the stigma and erasure faced by our patients extends, to a lesser degree, to us as clinicians. Historically, physicians in this field have been viewed as quacks or practicing on the fringe. While the members of our team have not been subject to harassment and death threats, as have colleagues in other states, we have received some negative attention from our community and peers.

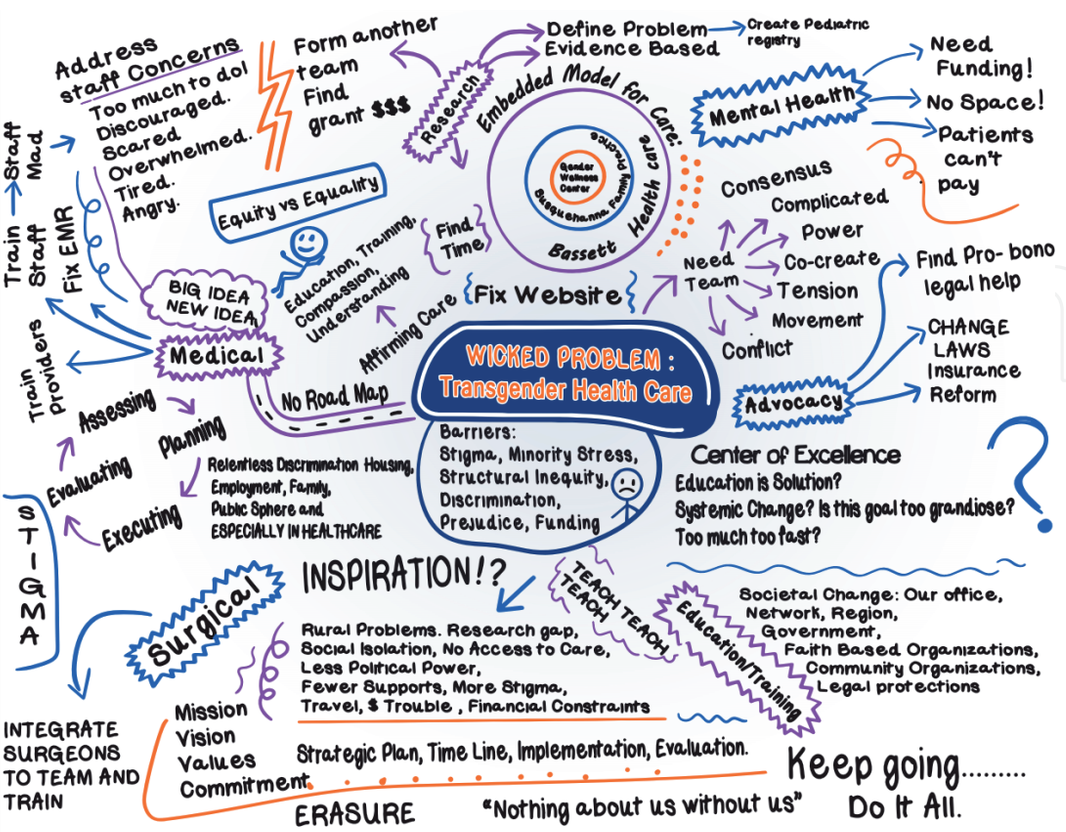


Figure 13.
The wicked problem of transgender healthcare.

Like many rural healthcare systems, our network faces financial challenges, leading to system wide cuts and the need to prioritize profitable programs over those that require funding to flourish. Typically, programs designed to address health care disparities are not money-making ventures. Our surgical program is potentially lucrative, though still small. Our medical practice brings in significant downstream revenue but like all primary care practices, struggles to stay in the black. Our mental health services are grant funded for limited terms [47]. We have come to understand that, by necessity, we will need to rely on grant funding for program sustainability.

Review of data collected through our pediatric registry indicates that our patient population is 89% white, a demographic that reflects our county, but not our larger catchment area. Communities of people of color (POC) in our region face additional barriers to care that our small rural clinic has been unable to address.

Our biggest challenge has been that our *wicked problem* is huge and there is too much to do. Our team members faced personal limitations around time and energy. It has been surprisingly difficult to move past personal differences to work on common goals as a functional team. These problems led to burn-out, a common problem for teams working on *wicked problems*, and one that requires us to reflect on problematic aspects to our personal styles or leadership skills.

Despite the challenges, we are proud to celebrate our program successes. Our team kept up with the increasing demands for services by expanding delivery of trans-competent and culturally responsive medical, mental health and surgical care to youth and adults. Our patients report high satisfaction with our services. We developed a vibrant research partnership to advance evidence-based care and trained numerous staff members, clinicians and healthcare professional students. We developed strong community partnerships with a number of regional CBOs, resulting in improved patient care and transformational personal relationships for ourselves. Our team sought and obtained grant funding to develop our nursing and mental health services and to develop a formal medical-legal advocacy program. Our center receives national recognition for our innovative work to create a new model for rural-based care.

We have also witnessed a significant regional shift toward moving transgender healthcare "from the margins to the mainstream." The shift is, in part, documented through our evaluation tools, but also comes to us in the form of stories from patients, community members and peers. An elderly cisgender man described a meaningful conversation with a young transgender woman in our waiting room. A physician from another network hospital sent us photos of their new gender-neutral bathrooms signs. A patient described being cheered after finding the courage to speak at a human rights rally on Main Street, in Oneonta. The physical therapy department reached out for training in order to better serve our patients. Bassett education arranged a visit with a prominent gender surgeon for a yearly celebratory teaching event and asked us to provide on-site rotations training for residents and medical students. Our network EMR will facilitate system-wide collection of SOGI data. Community mental health clinicians are flocking to our mental health training program. These stories illustrate profound systemic change at many levels in our community.

As individuals and as a group, we have benefited enormously from the RWJF leadership training. We studied how thought diversity and culture influence change and used personal assessment tools to gain a deeper understanding of our personalities and styles, and how these factors affect one another. Our team learned how to assess team roles and assign tasks to our strengths. Learning how to speak truth to power through the creation of a strategic plan, a business plan, and organizational charters proved exceptionally helpful. We learned to pay attention to the soft skills of interpersonal connection and learned to share leadership and responsibility for our work.

And finally, we learned that the process of bearing witness to the struggles and transformative journeys of our transgender patients challenges us to consider our own authenticity as human beings in a complex world. The word *privilege* may be used to describe unjust racial and class-based entitlement, a special birthright, an advantage. In hospitals, clinicians apply for and, if they meet qualifications for training and competency, are granted *privileges* -- the opportunity to practice under the auspices of that institution. This privilege includes how we benefit as individuals from our participation in the clinician-patient relationship. We are privileged to serve as guides through our patients' transformative journeys related to illness or health. We have all been profoundly changed by this work. The process of listening to and serving our patients in this complex world provides us with an extraordinary opportunity to learn, reflect and grow as individuals – an experience that, in small ways, mirrors the transformative change of our patients.

We've been asked by the RWJF Clinical Scholars directors to consider our legacy, a process that requires us to step back from the immediate and consuming project work to take the bird's eye view. Our hope is that, in our quest for excellence around rural-based transgender healthcare, our team has created a model for gender-affirming care that can and will be replicated in other primary care practices across the country. Our work is proof that a single patient asking for help from an uninformed clinician in a broken system can create a spark that drives that system to change. We have individually, as a group, and with our patients and community partners spoken out on the need to serve this at risk/at need population and have watched in awe as our system slowly and often painfully rose to the challenge. This model for care is our legacy and it rests in the collective ruckus raised from this work: the hubbub of direct patient care, the clamor of education and training, the din of legal advocacy and the rumpus of patient-centered research. This hullabaloo has pierced decades of erasure and neglect of transgender people in our region and led to the creation of a **Center for Exceptional Care in Transgender Health**.

It's a start. It's imperfect. We have all kinds of problems and still more to do. We say to you clinicians out there wanting to learn how to offer gender-affirming care from your primary care practice: *Go ahead. Do it. All big things start small. You will be profoundly changed by the trek toward this goal. We stand by you, cheering, as you make change happen too.*

7. Toolkit

To assist other clinicians to offer gender-affirming care using an embedded, primary care model we have created the following tool kit **(https://clinicalscholarsnli.org/community-impact)** of resources.

Acknowledgements

The author wishes to acknowledge the work of her teammates, Justine Woolner-Wise, LMSW, Christopher Wolf-Gould, MD, Diane Georgeson, MD, Patti Noon, LMSW, Susan Turell, PhD, Jackie Kelchlin, FNP, Anne Gadomski, MD, MPH, Nancy Tallman, Melissa Scribani PhD.

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Author details

Carolyn Wolf-Gould
The Gender Wellness Center/Susquehanna Family Practice, The Bassett Healthcare Network, New York, United States

*Address all correspondence to: carolyn.wolf-gould@bassett.org

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