

# Toolkit for the Creation of a Center of Excellence in Transgender Healthcare

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# **ABOUT THE PROGRAM**

Clinical Scholars is a national leadership program of the Robert Wood Johnson Foundation led by the University of North Carolina at Chapel Hill. Learn more about RWJF's Leadership for Better Health programs by visiting: rwjf.org/leadershipforbetterhealth

# **ABOUT THE TOOLKIT**

This toolkit can be used by providers and administrators who are developing medical and mental health practices and centers which provide care to transgender and gender non-conforming individuals. For more information, contact: (607) 431-5757

Photograph Credit: Molly Redden/The Guardian

# Toolkit for the Creation of a Center of Excellence in Transgender Healthcare

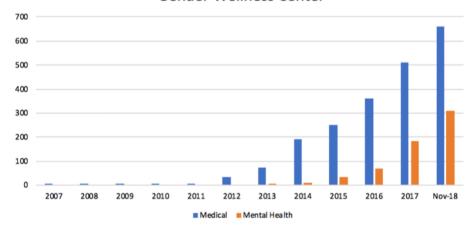
Every day, transgender and gender-nonconforming people face relentless discrimination in employment, family life, education, housing, and public accommodations, but some of the most appalling discrimination occurs when these individuals reach out for help - in healthcare settings. Transgender patients are among the most marginalized in our nation.

Over the last decade, cultural shifts in the United States have led to greater visibility and acceptance of gender diverse people and awareness of the significant healthcare disparities they face. This shift has resulted in a sharp uptick in demand for transition-related medical care. Addressing healthcare disparities for this population through service, research and education has become a national priority.





# Cumulative Numbers of Patients Seen in the Gender Wellness Center



Greater visibility and acceptance of gender diverse people and awareness of the significant healthcare disparities they face has led to an uptick in demand for transition related services.

# Interdisciplinary center for youth and adults

To address the lack of regional services, the providers at Susquehanna Family Practice in Oneonta, New York created an interdisciplinary center that now offers medical care for youth and adults, mental health services, and basic gender-affirming surgeries. In addition, the center has developed training programs, partnerships for legal advocacy, and a collaboration with the Bassett Research Institute for community-based research.



# **Planning**

Due to the complex biopsychosocial needs and the presence of numerous barriers to care, patients often required extra time and support from staff and clinicians. We quickly came to the realization that a comprehensive Center of Excellence (COE) would be essential to the provision of the varied services needed by this population. By necessity, the CEO would be involved in staff training, coordination of care with interdisciplinary services, collaboration with community-based organizations, schools and employers, and medical-legal advocacy.

# **KEY SKILL SETS**

In 2016, we formally assembled an interdisciplinary team including a social worker, two family physicians, a gynecologist and a physician assistant who had all shown interest in provision of this type of care. We recognized the need for medical, surgical, and mental health providers for the creation of a COE. Team members first developed skills in cultural and clinical competency. As the project developed, team members also developed proficiency in program development, administrative collaboration and community engagement.

# **FUNDING**

In order to meet the complex medical, mental health and surgical needs of this population, we explored funding opportunities which would allow expansion and improvement of services. We applied and were selected for Clinical Scholars, a national leadership program of the Robert Wood Johnson Foundation (RWJF), to fund strategic planning for the creation of a Center of Excellence (COE) in Transgender Health for the Bassett Healthcare Network. Additional funding has been provided by various organizations:

- Local charitable donations (individual) to the Friends of Bassett Healthcare Network Foundation; Unitarian Universalist Society of Oneonta grant; and stipends from presentations
- State Delivery System Reform Incentive Payment Project (NY) grant for center RN coordinator; New York Department of Health grant to increase access to mental health services; New York State LGBT Health and Human Services Network annual funding

# Additional links for project planning

- The Report of the US Transgender Survey 2015
- WPATH Standards of Care Volume 7
- Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons



# **TEAM COMPOSITION**

- Chris Wolf-Gould, MD\* GWC
   Director of Provider Training
- Diane Georgeson, MD\* –
   Gynecologist & Surgical Liaison
- Carolyn Wolf-Gould, MD\* GWC Director
- Justine Woolner-Wise, LMSW\* GWC Director of Mental Health Services
- Patti Noon, LMSW GWC
   Director of Training
- Susan Turell, PhD Psychologist

\*Clinical Scholars Fellow

# **Project work**

Our wicked problem was to explore the possibility of creating a rural-based Center of Excellence in Transgender Health for our region in upstate New York. We employ the embedded model for care, meaning that we offer trans-affirming services from within an established family practice.

# STRATEGIC PLANNING

To advance exploration around creating a COE, the GWC clinicians met frequently with the director of the Bassett Research Institute and her team at the Center for Evaluating Rural Interventions (CERI). With the assistance of CERI, we conducted focus groups with patients to assess community needs and created a logic model to explore project goals and the steps required to achieve those goals. We chose a number of project evaluation tools to assess project success.

We then hired a consultant to assist with strategic planning. Starting in July 2017, we conducted 25 individual stakeholder interviews, network/community surveys and a patient satisfaction survey. Stakeholder surveys focused on strengths, weaknesses, opportunities and threats regarding our existing program (*Appendix A*). In October 2017, stakeholders, including patients, employees from regional CBOs, network administrators and employees, and community members participated in two forums to review data from the surveys and make program development recommendations.

The clinical team then created a three-year strategic plan with five strategic directions, and specific goals for each direction. The plan (*Appendix B*) distributed to stakeholders included the five strategic directions of:

- 1. Developing infrastructure and organizational capacity;
- 2. Expanding awareness, knowledge and skills;
- 3. Fulfilling staffing needs;
- 4. Ensuring affirming care; and
- 5. Advancing evidence-based care.

We included members of the transgender community in all stages of our project. We formed a network advisory board, which included network employees and community members who identified as transgender or gender non-conforming. We created a research advisory board with nine members of the transgender community to help design and guide implementation of related research. This board has widened its scope by also serving as our community advisory board.

# **OPERATIONALIZATION OF STRATEGIC PLAN**

The remainder of the grant period was devoted to operationalizing the strategic plan. The clinical team met quarterly to assign projects, review the accomplishments, and assess, reflect, adjust and update the strategic plan.

Our team worked closely with an outside strategic planning consultant through periodic retreats to advance the planning process. With few models available for provision of this type of care in rural areas, our project involved the creation of a new



# KATE'S STORY: PART 1

Kate was born in upstate New York. Although she was assigned male at birth, she knew early in life that she was a girl. In college she presented as a feminine gay male but eventually came to understand that she identified as a woman. At the age of 35, she began presenting full time as a woman, and then experienced the loss of her job and family support as well as public harassment. She attempted suicide and was hospitalized multiple times for treatment of depression.

Kate was born with congenital heart disease, necessitating a lifetime of frequent medical visits. After transition she discovered that some of the most difficult discrimination she faced happened in medical settings. For example, when hospitalized for acute pulmonary failure she was subjected to a "full body check" in order to examine her genitals and determine her "real" gender. When she first sought gender-affirming hormone therapy she was ridiculed and denied care.

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model for provision of care. Our team expanded with the hiring of two additional clinicians who were integral to plan implementation. This allowed for a rapid increase in capacity of services provided.

# **ACTIONS**

- Created business plan (Appendix C) and built a new website
- Formed our network advisory board to facilitate integration into our larger healthcare network (*Appendix D*)
- Implemented our quality assurance program including monthly interdisciplinary rounds and quarterly chart reviews (*Appendix E*)
- Wrote policies for mental health services
- Created a robust provider training program that offers on-site training for regional medical students, residents, and medical providers
- Created a pediatric registry to advance evidence-based research around the care
  of transgender and gender non-conforming youth (*Appendix F*) and have begun
  publishing data from it and on other related topics (*Appendix G*)
- Responded to needs identified by the research advisory board (*Appendix H*)
- Employed Consolidated Framework for Implementation Research (Appendix I) to assess project implementation
- Took deliberate steps to ensure the creation of affirming health care spaces, including the provision of gender-neutral bathrooms at some network facilities
- Completed the Human Rights Campaign's Health Equity Index to ensure affirming hospital policies
- Sought grant funding to hire an RN coordinator to assist with patient care and case management

Our Vision is to bring transgender healthcare from the margins to the mainstream.

Our Mission is to provide comprehensive, affirming medical, surgical and mental health services to transgender and gender expansive people and their loved ones.

We Value interdisciplinary, evidence-based, culturally competent care for adult and pediatric patients with diverse gender identities

We Commit to training for healthcare professionals, community outreach, advocacy, and community-based research.

# **KATE'S STORY: PART 2**

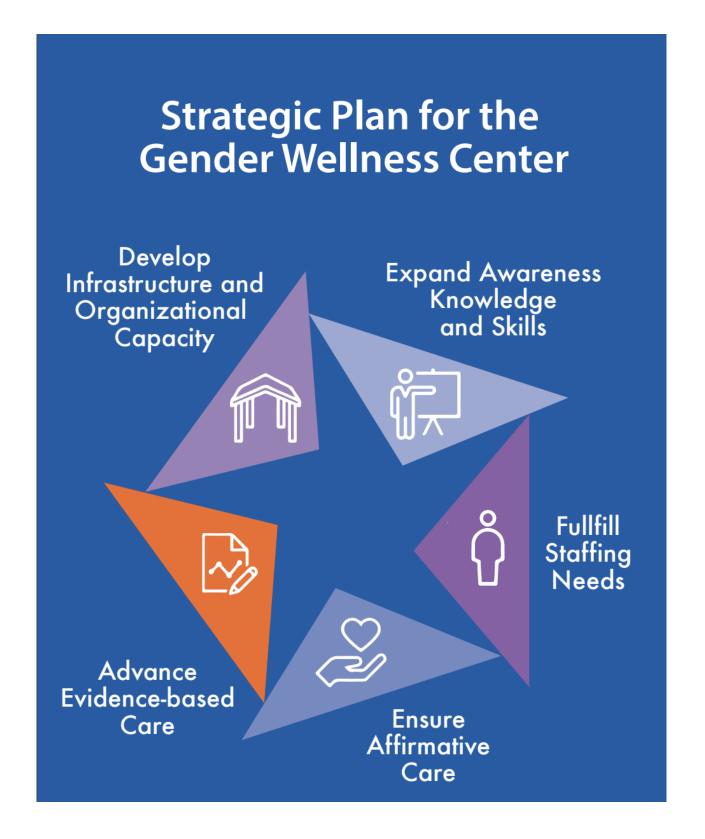
my own skin."

Kate finally found her way to The Gender Wellness Center, where her clinician prescribed gender-affirming hormones and referred her for gender-affirming surgery. These interventions allowed her to feel more herself, "1000% happier, more confident and more comfortable in

After medical transition she became an activist for transgender rights in the New York State Capital, and states that her advocacy work helped pull her out of her depression. She currently has both an active blog and Facebook page devoted to social activism.

Kate is also passionate about educating health care providers about transgender identities and genderaffirming care. She helped Gender Wellness Center clinicians develop a training program for medical students which has incorporated the use of transgender people acting as model patients. These trainings provide students an opportunity to learn and practice skills around cultural responsiveness. Her hope is simply:

"The next generation of doctors will be better".

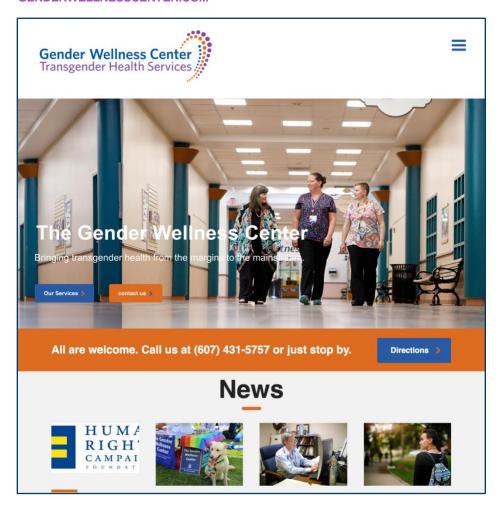




# **Evaluation and dissemination**

We have continually evaluated our project in collaboration with the Bassett Research Institute (BRI) which coordinates research and evaluation for our healthcare network. We tracked all medical and mental health patients served through our center and used Logic Models, Social Network Analysis, and the Consolidated Framework for Implementation Research (CFIR) for project evaluation. Our logic models depict steps required for program implementation. The Social Network Analysis has been completed annually and demonstrates the growth of our professional network both nationally and in our region. A post-project survey will be done using the CFIR structure, allowing us to create a final summary report. Additionally, we have tracked our strategic plan implementation over time. All on-site and didactic trainings were evaluated with pre- and post-event testing. We instituted quarterly chart reviews and established peer reviewed interdisciplinary rounds to assess and guide patient care.

#### **GENDERWELLNESSCENTER.COM**



# **KEY MESSAGES**

- Understanding of transgender identities;
- Cultural competency and humility for clinicians and medical systems; and
- Importance of an interdisciplinary approach to care.

Additional dissemination activities include the acceptance of 17 papers/abstracts generated from the work done at the Gender Wellness Center, with 7 posters presented at the biennial World Professional Association for Transgender Health (WPATH) conference in Argentina in November 2018.

In addition to our over 80 trainings and presentations, we are developing training modules for use throughout our network and GWC website. Our business plan documents both the financial and mission driven value of the GWC to our larger healthcare network and has helped us to attain network support to ensure sustainability.

# Challenges, successes, and lessons learned

Challenges to our work in developing an interdisciplinary Center of Excellence in transgender health fell into two broad categories: systemic and personal/interpersonal.

# **SYSTEMIC CHALLENGES**

**Breaking down silos:** Our team faced challenges working within a large healthcare network where care is physically and organizationally separated by specialty areas posed challenges to our interdisciplinary care team. There is no precedent for our embedded model of care and no administrative or clinical infrastructure for working across disciplines. It has been challenging for our medical and mental health clinicians to closely collaborate with our surgical team, as they are in a separate physical location.

Integration of Mental Health: We have struggled to integrate our mental health (MH) services into our family practice. We initially lacked resources to hire mental health clinicians and infrastructure to support their work on site. With assistance from a New York Department of Health grant, we are now beginning to integrate MH services into the GWC. In September 2019, our MH providers will be salaried as employees or consultants, allowing providers to access the patient's electronic medical record, and more closely collaborate with medical providers. Our counseling services will be free under this grant. We have not yet initiated billing for mental health services.

**Dealing with changing health care landscape:** During the course of our Clinical Scholars grant, our network has faced significant economic challenges. A major network-wide reorganization mid-project changed lines of supervision and leadership. Introduction of a new electronic medical record led to practice improvements, but required investment of time and energy.

**Financial challenges:** The current financial climate in health care makes it difficult to assure adequate support for new projects. This is challenging for a mission-driven initiative seeking long term sustainability.

# PERSONAL AND INTERPERSONAL CHALLENGES

**Transition to including specialized transgender care in an established family practice:** For some staff and patients of our traditional family practice, the inclusion of gender affirming medical and mental health care has been an uncomfortable transition. Not only is there a learning curve around acceptance and cultural competence, there are new medical protocols, integration of mental health, and increased time and attention given to serving a population that is deeply disadvantaged by health care disparities. This has been a strain on the staff of our family practice.

**Recruitment of transgender and GNC individuals:** "Nothing about, us without us" is an important directive from the transgender community. We have struggled to recruit and include significant transgender representation at all stages and levels of the project, due in part, to the rural nature of our community.



# LEADERSHIP, LANDMINES, OR LESSONS LEARNED

- Cultural humility and competency for health care providers is essential.
- Each person is on their own learning curve in terms of acceptance and cultural competency.
- "Nothing about us, without us" is an important directive from the transgender community
- There has been exponential growth in the provision of medical and mental health services.
- It is important to identify and engage stakeholders and "power brokers".
- Ongoing network support is key to building a sustainable program.

**Unrealistic workload:** Most of those involved have dedicated countless hours to this project well beyond the scope of their jobs. Maintaining a full clinical practice as well as creating a center of excellence, developing partnerships, engaging in research, training, and advocacy has been a time challenge for us all.

**No dedicated Administrator for GWC:** The lack of a dedicated administrator or manager has created challenges in getting the work done, and in our ability to "have a seat at the table" with network leadership. All clinicians have jumped in to fill these gaps as they continue the clinical aspects of the work.

#### **SUCCESSES**

**Developing infrastructure and capacity:** We succeeded in the creation, tracking, and implementation of our strategic plan. A Network Advisory Board has been created, and an administrative champion actively participates on this new board. A research/community advisory board has been established. An RN coordinator has been hired through outside grant support and the network has made commitments to make this a permanent position in the Center.

Implementation of a comprehensive marketing plan has begun, which includes the creation of a website and logo, and participation in community outreach activities. A completed business plan is being disseminated to network leadership in order to secure continued network support.

Capacity for provision of medical, mental health, and surgical care has expanded through training of new providers. Quality improvement projects are underway, through ongoing chart review and monthly interdisciplinary rounds.

**Training and research:** Our medical providers offer on-site training in transgender health care to medical students and residents, as well as physicians and nurse practitioners. As of August 2019, we have trained over 34 medical students/residents and 6 health care professionals while 11 presenters affiliated with GWC have provided 80 trainings to professional and community organizations on related topics.

Our electronic health record system was updated, giving it the capability to easily collect sexual orientation/gender identity (SOGI) data. Staff trainings on methods of data collection have been completed and widespread data collection is under way.

A pediatric registry has enrolled approximately 170 transgender, gender diverse children and youth. Current and future publications address the creation of the registry, and quality of life metrics for this population.

**Health equity:** On the Human Rights Campaign's Health Equity Index, Fox Hospital (our main affiliate) has achieved a 100-point rating for LGBTQ inclusion and received HRC's coveted "Leader in LGBTQ Healthcare Equality".



It is an honor to work with our patients/clients and be a part of a movement that is strengthening our culture.

# Recommendations

Input from the transgender community is essential during project planning and implementation.

- It is important to identify and engage stakeholders.
- Business, organizational development, and administrative skills are necessary for success.
- Collaboration and networking with community-based organizations maximizes impact.
- Effecting change within a large, complex network/system requires strategic planning.
- Self -awareness in terms of implicit bias and conflict and change styles is valuable.
- Effective communication, persuasion, and messaging skills enhance a project's success.
- Leadership comes from collaboration. Leaders listen. Leaders emerge because they are followed.
- It is important to not grow faster than your capacity to provide and maintain high quality service.

# **GETTING STARTED**

In tackling this issue in your community, the first thing to do is to collaborate with members of the transgender/gender diverse community to deepen your understanding of their needs. This can be done through surveys, focus groups, formation of a community advisory board, and informally through personal interactions with individuals.

Be aware that resistance to change, and transphobia are inevitable – otherwise the problems would be easily solved. Not everyone can be convinced about the importance of this work. However, allies can be found in most situations, and can be leveraged to catalyze institutional change. In our project, a high level of engagement with the surgical department and our research institute gave validity to our mission.

As with any type of social change, one must have a high tolerance for ambiguity, and expect continual change as the process unfolds. Staff turnover, policy initiatives, and financial factors may all impact the work.

# **BEST PRACTICES**

Partnering with other individuals and organizations allowed rapid amplification of our impact. Systemic change is difficult, but not impossible to achieve. Finding the right balance between thorough planning and a "just do it" approach is necessary to maximize success. Groups and individuals across the country with vision and passion for this work served as sources of inspiration.

This work can be all consuming, and both excitement and disappointment are inevitable. Conflict within the movement, and with outside forces are ever present, and can be quite stressful. However, it is important to savor the process and enjoy the many successes, and to maintain one's composure when faced with obstacles.

# **Appendix**

# APPENDIX A: BASSETT HEALTH CARE STAKEHOLDER INTERVIEW QUESTIONS

Interviewer:	nterviewee:	Date:
QUESTION		RESPONSES
	Gender Wellness Center and for how long? I'd are you about us so that I ask appropriate	
What do you see as our strongest asset	ets?	
In what way does the work of the Gene Care Network?	der Wellness Center add value to Bassett Health	
How does the GWC detract from the v	alue of the Bassett Health Care Network?	
What are the challenges in the health about which we should be mindful?	care landscape at Bassett Health Care Network	
What are the notable trends, forces of Insurance, (other?)	change, or shifting needs that we should plan for?	
What key external factors may hinder	our success? Where are the minefields?	
What key internal factors may hinder of	our success?	
What about our specific work gives you	u pause or caution?	
What are key opportunities for us to co	onsider?	
services, and surgical services. What	medical care for youth and adults, mental health organizational models should we consider, to approach to care within the Bassett Health Care	
	e our model of embedding transgender health care specialty center for care of transgender people?	
What have you heard regarding the im transgender people on the rest of our p	pact of our extensive and unique work with practice?	
What partnership opportunities should	we be exploring?	
in the country. The definition of "center	ased Centers of Excellence in Transgender Health of excellence" is vague. In your mind, what does hould we include and what (if any) should we	
	ucation for medical students, residents and other de the Bassett Health Care Network? How can d?	
	e mental health providers who provide services at el. We are unable to bill insurance. What model of th services?	
What role should the GWC serve in fur this happen?	thering community-based research? How should	
	ulti-disciplinary center for TG health in Upstate, ve as a resource for other places in upstate, NY?	
What kinds of educational programs sh	nould the GWC provide throughout the network?	
Do you know how to prescribe PrEP? (prescribe PrEP? Would you send your	(pre-exposure prophylaxis for HIV)? Do you patients to the GWC for PrEP?	
underserved population. Are there other	t edge of providing medical care to a new and ers models in healthcare that have already moved we could learn from? What is the learning?	
In summary, what advice do you have	for our future?	

## APPENDIX B: THE GENDER WELLNESS CENTER STRATEGIC PLAN - NARRATIVE SUMMARY NOVEMBER 2017

The Gender Wellness Center (GWC) of the Bassett Healthcare Network is a nationally recognized, rural-based multidisciplinary center that offers affirming medical, mental health and surgical care to gender nonconforming and transgender people in upstate, New York. In 2017, an interdisciplinary team of providers from the GWC was awarded a Robert Wood Johnson Foundation (RWJF) Clinical Scholars Grant to investigate the possibility of creating a Center of Excellence (COE) in transgender health for the region. The mission, vision and values for the GWC align with those of the Bassett Health Care Network, and advance the ability of the Network to reduce health care disparities for sexual and gender minorities (SGM).

**Our Vision** is to bring transgender health from the margins to the mainstream.

**Our Mission** is to provide comprehensive, affirming medical, mental health, and surgical services to transgender and gender nonconforming people and their families. We Value evidence based, culturally competent care for pediatric and adult patients with diverse gender identities. We Commit to training for health care providers, community outreach, advocacy and community-based research.

In August of 2017, the GWC clinicians held focus groups, and conducted a network/community survey and patient satisfaction survey to identify strengths, weaknesses, opportunities and threats to the existing program. In October, 2017, our team held a strategic planning event, facilitated by Nancy Jackson, MSW, to create a three-year strategic plan. We offered two forums for Bassett employees, patients and regional community members to review data from the focus groups, surveys and offer input for developing a Center of Excellence. Our clinical team then created a three-year plan with five strategic directions:

- 1) Developing infrastructure and organizational capacity
- 2) Expanding awareness, knowledge and skills
- 3) Fulfilling staffing needs
- 4) Ensuring affirming care
- 5) Advancing evidence-based care

Operationalization of this strategic plan will strengthen the ability of the GWC to realize its mission, vision and values and serve as a regional leader for patient care, legal advocacy, training, and community based research. Our team will follow, monitor, and ensure progress of the strategic plan by creating a detailed timeline with appropriate delegation of responsibilities. We will reassess our plan on a yearly basis and make appropriate adjustments. Funds and training from the RWJF are available to assist with operationalization of our strategic plan through August, 2019.

Details of the strategic directions are detailed as follows:

# (1) Developing Infrastructure and Organizational Capacity:

A strategic priority is to designate the GWC as a formal entity within the Bassett Healthcare Network. This will clarify our role, ensure adequate administrative support, catalyze growth and enhance sustainability of our program. We will work with the Bassett Administration to determine the most effective type of entity, exploring the possibility of becoming a service line, an institute or a formal center of excellence.

To facilitate the above process, we will seek administrative assistance from within the Bassett Network. We will ask members of to serve on an administration advisory board and help to appoint an administrative champion to partner with our clinical team. With the assistance of this advisory board and champion, we will create organizational charts and Venn diagrams to define the relationship of the GWC to Susquehanna Family Practice, and the place of the GWC/SQFP within the network. We have determined that the best model for comprehensive care and project viability is to continue to embed the GWC within Susquehanna Family Practice (SQFP).

We will ask for administrative assistance in exploring space needs within the Fox Care Center to accommodate expanding services. With administrative support, we will ensure that a financial analysis, business and marketing plan are completed to define financial viability and assure the sustainability of our program. This will include analysis of our current financial status, identification of internal and external funding sources and a plan for developing grants. We will work with network administrative staff to create a GWC brand, a marketing plan and to update our website.

We will establish formal policies and procedures around the work of the GWC, including patient screening, referral processes, and quarterly Q/A for medical, mental health and surgical providers.

We will establish a monthly meeting for interdisciplinary peer review of complex cases. We will follow the Endocrine Guidelines (1) and WPATH SOC7(2) to ensure that youth receive appropriate interdisciplinary review for any irreversible or partially reversible medical interventions.

We work with the network administration to ensure that all network hospitals update their policies and procedures to ensure LGBT affirming care by completing the Human Rights Campaign's Health Equality Index.

We will continue to work with The Network Healthcare Disparities Working Group and Bassett IT /EPIC team to operationalize collection of Sexual Orientation/Gender Identity demographics throughout the network.

We will delineate clear roles for clinicians and staff in the GWC.

We will create a community advisory board to facilitate input from the community to the GWC team.

We will continue to develop relationships with regional Community Based Organizations who serve the LGBT population.

# (2) Expanding Awareness, Knowledge and Skills:

We will continue to provide training in cultural competency and clinical care for SGM by participation in grand rounds, and offering educational events throughout the network and community.

We will develop onboarding plans for education and training of all new clinical or staff hires in the GWC. The team will extensively train new surgical, medical and mental health providers who join our center.

We will facilitate training for network surgeons who wish to develop advanced skills in gender affirming surgical care.

We will participate in national and international educational conferences, as attendees, organizers and speakers. When possible, we will continue to fund attendance at conferences for students and members of the Bassett Research Institute (BRI) presenting research generated through work at the GWC. All conference participation will be tracked and reported yearly.

We will continue to coordinate with medical education at MIBH and outside institutions to develop clinical rotations for students and residents. The effectiveness of these rotations will be assessed with pre and post testing. Capacity for the training of medical students, residents, nurse practitioners, and physician assistants through our center will be measured and maximized using our current providers. If additional providers become available, increased number of trainees can be served.

We will work with Bassett PR to educate the network about our program through regular newsletter updates.

We will develop an educational plan for provisions of LGBT affirming primary care for network-wide providers to increase regional availability of affirming primary care.

# (3) Fulfilling Staffing Needs:

The filling of current and future staffing positions is a strategic priority.

An appropriate person will be hired to fill the vacant position of Office Manager for the GWC and SQFP. The position of Patient Centered Medical Home (PCMH) RN for the GWC/SQFP will be advertised and filled.

Two to three additional medical providers (for both primary and gender care) will be recruited and hired for the GWC/SQFP. Jackie Kelchlin, FNP will be the first, starting in December, 2017. Efforts to recruit an additional provider will begin in the spring of 2018.

Our team will work with the administrative advisory board and our administrative champion to develop a sustainable model for mental health services. It may be necessary to hire a project manager to assist in the creation of this model. We will move from a private practice model, to an employed model for our mental health providers so that all mental health clinicians have access to the EPIC EHR system. We will explore grants to fund mental health services, and assess the possibility of involving appropriately licensed clinicians so that our providers can bill insurance. We will create and fill the position of Director of Mental Health for the GWC.

We will develop formal collaboration with child and adult psychiatrists with skill in transgender health. We will explore tele-health options if the network does not have appropriate providers.

We will continue to pursue a grant through DSRIP to fund the position of RN Coordinator for the GWC. The RN coordinator will assist with case management, education, research and operationalization of the strategic plan.

We will develop ways to better integrate the network surgeons providing gender-affirming surgeries into the GWC clinical team. We will explore the possibility of rotating surgical staff through the GWC office, and expanding the kinds of gender surgeries offered throughout the network. Surgeons will be invited to attend interdisciplinary rounds.

We will explore formal collaborative agreements with available legal consultants to provide legal advocacy for patients and explore grants to fund this position.

We will develop the position of training coordinator for the GWC. This person will work with The Institute of Gender, Relationships, Identity and Sexuality (TIGRIS) to develop network and community trainings on cultural competency and other aspects of community based and/or patient care.

We will create a list of network and community partners with interest and expertise in areas that relate to our strategic directions. These experts will be asked to assist with specific strategic initiatives, such as creating a business plan, branding, exploring value-based insurance contracts, grant development, etc.

We understand the importance of diversity and inclusion in efforts to reduce health care disparities for this patient population and commit to addressing the need for diversity in our recruiting efforts.

# (4) Ensuring Affirmative Care:

We recognize that addressing health care disparities for a marginalized population requires particular dedication and skills from our staff. We will ask Bassett administrative staff and our administrative champion to help us "change the narrative" so that our office staff understand the principles of health equity and their value to the network for this work. Our staff will receive ongoing training and opportunities to participate in operationalization of the strategic plan, if interested.

We will develop an office covenant/operating principle to define expectations around affirming treatment for all patients at the GWC and SQFP. This document will be used in all efforts to recruit, interview and orient new staff to SQFP/GWC.

We will assess visual cues in the waiting room and office space of SQFP/GWC to ensure creation of space that is welcoming to LGBT patients.

We will explore whether the Press-Ganey patient satisfaction surveys can incorporate ways for responders to identify as members of LGBT community, so that we are able to measure and monitor patient satisfaction.

We will request that gender-neutral bathrooms be readily available throughout the network. A 50% increase by 2019 of available gender-neutral bathrooms in the Foxcare Center and Fox Hospital is one measurable goal incorporated into this plan. We will work with building and grounds to be sure appropriate signage is used for these restrooms.

We will work with Karen Huxtable-Hooker and Carolyn Handrick from Bassett PR to update our web site.

We will ensure that patients are able to access Pre and Post Exposure Prophylaxis for HIV through our office.

Some of our medical providers will be licensed and trained to offer LGBT affirming Medication Assisted Therapy to patients with drug and/or alcohol addiction.

We will request that a transgender individual serve on the Fox Hospital Ethics Committee to ensure an informed process for review of complex cases.

# (5) Advancing Evidence-Based Care:

We will continue to work with the Bassett Research Institute on community-based research efforts. This includes development of a pediatric registry, and possibly the creation of an adult registry. We will work with the BRI to explore grants for research efforts. The GWC and BRI will complete five publications/abstracts annually.

The GWC/BRI team will continue to offer collaboration with medical students and residents who wish to work on research projects on transgender health.

We will develop quality measures for our medical, surgical and mental health care and participate in quarterly peer chart review through Quality Management Services at Fox Hospital.

- 1. Hembree WC, Cohen-Kettenis PT, Gooren L, et al. Endocrine Treatment of Gender- Dysphoric/Gender-Incongruent Persons: An Endocrine Society\* Clinical Practice Guideline. *J Clin Endocrinol Metab*. 2017;102(11):3869–3903.
- 2. Coleman E, Bockting W, Botzer M, et al. Standards of care for the health of transsexual, transgender, and gender-nonconforming people, version 7. *Int J Transgenderism*. 2012;13(4):165–232.

Carolyn Wolf-Gould, MD Justine Woolner-Wise, LMSW Christopher Wolf-Gould, MD Diane Georgeson, MD Patti Noon, LMSW November, 2017

### APPENDIX C: BUSINESS PLAN EXECUTIVE SUMMARY

#### Introduction:

The purpose of this report is to demonstrate the financial and reputational value of the Gender Wellness Center (GWC) at Susquehanna Family Practice to the Bassett Healthcare Network (BHN), and to ask the BHN network leadership to provide specific financial and organizational support to the GWC to ensure program sustainability and expansion.

The financial value of the GWC is based upon our provision of a unique service, which draws a majority of patients from outside the BHN catchment area. Revenue is derived from office visits at the GWC as well as from utilization of ancillary services at multiple sites. In addition, referrals to specialists within the network provide a source of revenue that would not have previously existed. Finally, surgical services bring significant professional and hospital-based revenue to the network. All of these services have a potential for growth and development.

Our reputational value stems from the GWC's mission driven commitment to excellence in education, outreach, medico-legal advocacy and community-based research. The mission and vision of the GWC intentionally aligns with that of the BHN. Our reputation as a center that meets the diverse needs of a population with significant health care disparities has brought national attention to the BHN.

With the assistance of the Robert Wood Johnson Foundation (RWJF) Clinical Scholars grant, the GWC clinical team plans to celebrate the establishment of the first rural-based Center of Excellence (COE) in transgender health in the U.S. by the end of the grant period, September 2019. We require support from the BHN leadership at this juncture in order to achieve this goal.

# Mission, Vision and Values Statement:

The mission, vision and values of the Gender Wellness Center/Susquehanna Family Practice (GWC/QFP) intentionally align with the mission, vision and values of the Bassett Healthcare Network.

The GWC specifically advances the stated mission and vision of the BHN as follows:

By garnering the trust of transgender patients and their families in the provision of high quality, evidence based, affirming, interdisciplinary care

By achieving national recognition as a sophisticated, integrated, rural transgender healthcare center

By providing transgender healthcare training for graduate, undergraduate and allied health professionals and staff

By attaining national and international recognition for transgender health research in a rural environment

By bringing innovation to the BHN around addressing healthcare disparities in our region and beyond.

# Background:

Every day, transgender and gender-nonconforming people face relentless discrimination in employment, family life, education, housing, and public accommodation, but some of the most appalling discrimination occurs when these individuals reach out for help -- in healthcare settings. Transgender patients are among the most marginalized in our nation.

Over the last decade, cultural shifts in the United States have led to greater visibility and acceptance of gender diverse people and awareness of the significant healthcare disparities they face. This shift has resulted in a sharp uptick in demand for transition related medical care. Addressing healthcare disparities for this population through service, research and education has become a national priority. 1–3 As the regional leader in the provision of culturally and clinically competent medical, surgical and mental healthcare for transgender people, Bassett's Gender Wellness Center is well placed to leverage our competitive edge in the field and lead the development of trans-affirming healthcare services for upstate, New York. At the time of this report, the GWC medical providers have served over 650 transgender medical patients and 283 mental health patients from our region. 7

As evidence of our national recognition, in 2016, the GWC received the prestigious three-year leadership development grant from the RWJF to investigate the possibility of developing the first rural-based COE in transgender health for the country.

A Center of Excellence is a specialized program within a healthcare institution which supplies a concentration of expertise and resources related to a particular field, and delivers care in a comprehensive, interdisciplinary fashion. 4 COEs are developed to create cultures that put patients first, keep people healthier and out of the hospital and plan for value-based care. 5 Clinicians in a COE provide leadership, demonstrate best practices, measure quality, conduct research, and offer support and/or training for a focus area. The purpose of this business plan is to demonstrate specific, measurable results achieved toward this purpose after our first two years of the RWJF grant. After two years of work, we have expanded competent and affirming services for transgender medical, mental and surgical health within the BHN and have developed effective programs in medical education, community-based research and medico-legal advocacy. Moving forward, we are well positioned to capitalize on reimbursement from patient services and to seek opportunities for grant funding. Our plan is to formally designate the GWC a COE with a ribbon cutting event at the end of our RWJF grant period, in September 2019.

# Highlights of Business Plan:

This business plan describes the history of the GWC, its current business model and offers a path for stabilizing and expanding both clinical and non-clinical services. The GWC clinical team is aware of the financial and organizational challenges facing our network at this time. This business plan clarifies necessary steps to ensure that the GWC is financially sound and aligned with the BHN mission and vision.

This business plan describes the financial gain to the BHN from the GWC program through its medical and surgical services. It explores avenues for financial growth in these areas, particularly gender-affirming surgical care. It describes the potential financial impact of being able to bill for mental health services provided in the GWC by incorporating our mental health program into the network. This business plan is based upon our current fee-for-service model. We are cognizant of planned changes in reimbursement based on population health and value-based purchasing.

Our model for care and organizational infrastructure will give the BHN a competitive edge in negotiations with payers around coverage for this high risk/high needs population as we move into the future. Similarly, we are aware of proposals to restructure services at the FoxCare Center (FCC) and have created this business plan with flexibility around potential upcoming changes. Central to our business plan is the need to move transgender healthcare from the margins to the mainstream by embedding services within our thriving family practice.8

# Keys to Success: "The Ask"

Success in creating a rural-based COE for transgender health in our network depends on the ongoing support of the Bassett leadership to stabilize and expand services while operationalizing our strategic plan. We ask the BHN leadership to support our efforts to change the culture of health and overcome systemic challenges so that we are able to provide excellent and equitable healthcare services to transgender patients.

Specifically, we ask the BHN leadership to:

- Commit to the development and funding of an administrative position to assist with advancement and oversight of our interdisciplinary practice
- Assist us to define and formalize our place as an interdisciplinary center within the organizational structure of the BHN
- Recognize the fundamental importance of our mental health services to the work of the GWC clinical team and support efforts to integrate mental health services within the GWC/BHN
- Commit to recruitment and hiring of new providers for our medical, surgical and mental health services, and to ongoing support for the GWC RN coordinator position
- Identify outside funding sources for services, education, advocacy and research and assist with grant writing
- Allocate adequate space for our interdisciplinary team
- Support the non-clinical work of our clinicians around research, advocacy, administration and teaching
- Support the development of tele-health services for mental health and medical services
- Assist us as we plan for succession 9

# **Executive Summary Conclusion:**

As a Center of Excellence in Transgender Health, the GWC of the BHN will be the first rural-based COE in for transgender health in the nation. This mission driven organization brings significant revenue as well as recognition and distinction to the BHN. Success in creating a COE requires commitment from the BHN to fully embrace the mission and vision of the GWC and support the development and sustainability of our services. We ask that the BHN leadership recognize the value of the GWC and provide financial and organizations support at this critical time.

### APPENDIX D: NETWORK ADVISORY BOARD CHARTER

# GENDER WELLNESS CENTER (GWC) NETWORK ADVISORY BOARD CHARTER 3/26/18

PURPOSE: To support the Mission, Vision and Strategic Plan of the Gender Wellness Center within the Bassett Healthcare Network and provide non-binding strategic advice to the management of GWC.

SCOPE: The Gender Wellness Center is located within Susquehanna Family Practice at FoxCare Center in Oneonta, NY and offers comprehensive, multidisciplinary care to transgender and gender diverse patients throughout the upstate NY region.

FUNCTIONS: To meet quarterly and review progress of the GWC strategic plan, assuring activities and initiatives are in alignment with our mission, the Networks' mission and the needs of the communities we serve.

MEMBERSHIP: Representatives from the leadership of the Bassett Healthcare Network and A.O. Fox Hospital, Departments of Outpatient Medicine, Surgery, Psychiatry, Pediatrics, BRI, our Foundation Boards, Finance, Marketing and Patient Experience, and Transgender Clients and community stakeholders.

MILESTONES: Regular review of Strategic Plan initiatives with assurance that goals are being met within the time frames established in the Strategic Plan.

BENEFITS: The Board will help develop resources and financial plan for ongoing sustainability within the Network.

CRITICAL SUCCESS FACTORS: The GWC has the resources to provide ongoing, interdisciplinary quality care to the patients we serve. The Network continues to receive recognition for this work.

# APPENDIX E: MEDICAL CHART AUDIT FORM

EPIC Medical record #, Date of Service, Prescribing Clinician, Reviewer.

Medical Chart Audits for the GWC: Adult patients who present to GWC for follow up care on Gender Affirming Hormones. Review based on standards from WPATH Standards of Care, Version 7 and the UCSF Center of Excellence in Transgender Health Online protocols.

1. Has the SOGI table been filled out?		
2. Has the patient had measurement of hormone levels after 3-6 months on treatment?		
3. If on Testosterone, has patient had CBC in the last year?		
If on Spiro, has the patient had a basic chemistry panel in the last year?yesno		
4. Have appropriate routine screening tests been recommended? (based on body parts gender)		
5. Have appropriate doses of gender affirming hormones been prescribed, through appropriate modalities (i.e. injectable, topical, oral) according to UCSF COE protocols?yesnon/a		
6. Has the patient been assessed for hormonal related physical change? yesnon/a		
7. Has the patient been assessed for transition related change in mental health?yesnon/a		
This chartmeetsdoes not meet WPATH Standards of Care for treatment of gender dysphoria.		
Comments:		
If care does not meet criteria, chart will be referred to prescribing clinician for review.		
Signed: Date:		

# APPENDIX F: BASSETT MEDICAL CENTER NEWSLETTER ABOUT PEDIATRIC REGISTRY

"Bassett Pediatrician Creates State's First Rural Pediatric Registry to Study Health Outcomes among Transgender and Gender Nonconforming Youth"

January 2, 2018 Cooperstown, NY – "There is not a lot of evidence to help inform clinical care of transgender and gender nonconforming youth, particularly for rural areas," explains Anne Gadomski, MD, pediatrician and director of the Bassett Research Institute in Cooperstown, NY. Gadomski was recently recognized by the NYS Department of Health for her work in support of gender wellness; she received the Worlds AIDS Day NY Commissioner's Special Recognition award for establishing New York State's first rural pediatric registry for transgender and gender nonconforming youth. It is also believed to be the country's first rural-based registry for transgender youth.

"The information we are compiling will help us address outcomes in youth and young adults receiving transgender care at the Bassett Healthcare Network Gender Wellness Center," explains Gadomski. "It's going to provide outcome information about the youth and young adults receiving transgender care, which will be used to inform evidence-based care going forward."

Participation in the registry is voluntary; currently, there are 113 patients participating who are in various stages of transition. The pediatric registry includes diagnoses, treatment, lab results and outcomes. The initiative was presented last November at a national scientific meeting in San Francisco by two of Bassett's researchers, Jane O'Bryan and Kim Leon, who helped develop the registry.

Gadomski says, "We expect that the database will increase practitioner understanding of specific clinical conditions and patient health care needs as well as help us identify trends that result from different interventions. Our goal is to continue to improve the care of transgender and gender nonconforming pediatric patients. Using the registry, we'll also try to answer specific research questions such as, "Do psychological outcomes improve over the course of gender-affirming care?"

Carolyn Wolf-Gould, MD, who founded the Gender Wellness Center and nominated Gadomski for the state award, says, "Anne's tireless efforts on behalf of our patients have made a tremendous difference already and this registry is another major step forward in advancing the care of transgender individuals."

Gadomski was also instrumental in securing Robert Wood Johnson Foundation funding for the Gender Wellness Center in Oneonta, which is working to become a center of excellence for transgender care and provide comprehensive, affirming medical, surgical and mental health services for gender nonconforming people and their loved ones.

# **APPENDIX G: PUBLICATIONS**

- 1) O'Bryan J, Leon K, Wolf-Gould C, Gadomski, A: "Prevalence of Non-Suicidal Self-Injury and Eating Disorders Among Transgender and Gender-nonconforming Youth at a Rural Gender Wellness Center." 16th Trans Health Conference, Philadelphia, PA, September 7-9, 2017.
- 2) Riley MR, Scribani MB, Denny D, Tallman N, Gadomski A: "Using Focus Groups to Validate Existing Needs Assessments for a Rural Transgender Population. Paper symposium: Challenging Perspectives: Are Evaluators Serving LGBT populations equitably? American Evaluation Association Annual Conference, Washington, DC. November 9, 2017.
- 3) GadomskiAM,Wolf-GouldC,Wolf-GouldC,Woolner-WiseJ,GeorgesonD. "Developing a center of excellence in transgender health: Implementation challenges and successes." 10th Annual Conference on the Science of Dissemination and Implementation in Health, Arlington, VA, December 4-6, 2017.
- 4) Gadomski AM, Wolf-Gould C, Wolf-Gould, C, Georgeson D, Woolner-Wise J, Noon, P. Using an implementation science framework to evaluate a Center of Excellence for Transgender Healthcare, EERS Conference, Canada, 5/1/18
- 5) O'Bryan, Jane 2017 National Transgender Health Summit in Oakland, CA "Building a Pediatric Patient Registry to Study Health Outcomes Among Rural Transgender and Gender-nonconforming Youth."
- 6) Madeline B Deutsch, Jamison Green, JoAnne Keatley, Gal Mayer, Jennifer Hastings, Alexandra M Hall, Rebecca Allison, Oliver Blumer, Stephen Brown, Mary Kay Cody, Kristopher Fennie, Gwen Moscoe, Rachael St Claire, Moonhawk River Stone, André Wilson, Carolyn Wolf-Gould: Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group, DOI: http://dx.doi.org/10.1136/amiajnl-2012-001472 700-703 First published online: 1 July 2013
- 7) Wolf-Gould, C: History of Transgender Medicine in the US, SAGE LBGTQ Encyclopedia, 2016
- 8) Wolf-Gould, C. & Wolf-Gould, C. Testicular Cancer in Transgender Woman: A New Twist on an Old Problem LGBT Health 2/16
- 9) Wolf-Gould, Carolyn, Letting Go, A Collection of Essays, Editor: Martha Hughes

10)O'Bryan J, Leon K, Scribani M, Wolf-Gould C, Gadomski A, Using a patient registry to study health outcomes among rural transgender and gender nonconforming youth, Pediatric Academic Societies, May 2018, Toronto

11)Leon K, O'Brian J, Scribani M, Wolf-Gould C, Gadomski A. Prevalence and predictors of non-suicidal self-injury among rural transgender youth, Pediatric Academic Societies, May 2018, Toronto

12) Family Oriented Medical Care for Gender-nonconforming Children, Adolescents and Their Families, Carolyn Wolf-Gould, MD, Chapter, Families in Transition: Parent Perspectives on Raising the Gender-nonconforming or Trans Child. Ed by Arlene Lev, LCSW-R, Andrew Gottlieb, PhD, Harrington Park Press, 2019 New York

13)Lev, AI, Wolf-Gould, CS, Collaborative Care Across Disciplines, Chapter in The Gender Affirmative Model: A New Approach to Supporting Gender Nonconforming and Transgender Children, Edited by Colton Keo-Meier, PhD, Diane Ehrensaft, PhD. APA, May, 2018

14) Murchison, G., Adkins, G., Conard, A., Ehrensaft, D., Elliott, T., Hawkins, L., Lopez, X., Ng, H., Wolf-Gould, C., Supporting and Caring for Transgender Children, Human Rights Campaign, September 2016

15)O'Bryan J, Wolf-Gould C, Matsuo Y (2018) Mammary myofibroblastoma in a transgender patient on feminizing hormones: literature review and case report, Transgender Health 3:1, 1–9, DOI: 10.1089/trgh.2017.0026.

16) Wolf-Gould, C & Wolf-Gould, C, Primary and preventative care for transgender patients, Comprehensive Care of the Transgender Patient, Ed Cecile Ferrando, Elsevier Press, 2020

17) Wolf-Gould, C, Riley, M, Carswell, J (2018) A trans-feminine youth with a BRCA1 mutation: a case study, LGBT Health Volume 5, Number 4, DOI: 10.1089/lgbt.2017.0148

18) Wolf-Gould, C, Riley, M, Carswell (2018) Complex Medical Decision-Making for a Trans-Feminine Youth with a BRCA1 Mutation, LGBT Health, Volume 5, Number 4, 2018DOI: 10.1089/lgbt.2017.0149

\*Seven posters and one oral presentation were delivered to the World Professional Association for Transgender Health Symposium in Buenos Aires, Argentina in November 2018 and are not included on this list.

# APPENDIX H: RESEARCH ADVISORY TEAM CHARTER

Charter for the Gender Wellness Center/Bassett Research Institute Community Research Advisory Team (CREATE)

# Purpose:

The Community Research Advisory Team (CREATE) to the Gender Wellness Center/Bassett Research Institute (GWC/BRI) provides the GWC/BRI research team with independent advice and critical feedback on the data collected at the Gender Wellness Center and the research methods used in our program. Here we define the community as all of the gender diverse people living within the GWC's catchment area. The Community Research Advisory Team will serve as a source of guidance in: 1) interpreting data, 2) identifying research problems appropriate for study, 3) providing feedback on research methods and techniques that are respectful of and acceptable to the community 4) assisting us in informing the trans community the results of our research.

# Rationale and Background:

To achieve our goal of Advancing Evidence-Based Care through research in our rural-based clinical environment we must design innovative studies that work for our system and for our patients. To do this, we must ensure that the research performed is designed for patient and population health outcomes and is acceptable and feasible to communities and their needs. We recognize that

research in resource-limited settings carries an increased risk of harm. Research can be extractive of communities or pull resources away from the delivery of essential services. Involving community input in all phases of research will allow us to prioritize community needs and minimize potential harm. The CREATE will bring together leaders and stakeholders from appropriate sectors of the community. This team will also advise the implementation and research team on evaluating the risks and benefits of research, setting research priorities, and once priorities are set, providing input and resources for the team's research activities. The CREATE will also be at the forefront of garnering support and promoting involvement of the greater community in the research. Ultimately, the CREATE will help implement research that aims to address the community's most pressing problems through the active participation of the Community.

# APPENDIX I: CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH ABSTRACT

"Using an implementation science framework to evaluate a center of excellence for transgender healthcare"

Anne Gadomski, MD, MPH1, Christopher Wolf-Gould, MD2, Carolyn Wolf-Gould, MD2, Justine Woolner-Wise, LMSW2, Patti Noon, LMSW2 and Diane Georgeson, MD2, (1) Bassett Healthcare Network, Research Institute, Cooperstown, NY, (2) Bassett Healthcare Network, Gender Wellness center, Oneonta, NY

**Abstract:** Given many barriers to health care, transgender (TG) people forgo medical care, self-treat gender dysphoria and experience health care disparities including increased rates of HIV infection, substance abuse, mood disorders and suicidality. Clinicians are often uncomfortable with TG patients due to inadequate medical training, limited evidence base for best practices, and lack of insurance, mental health and community resources.

The Consolidated Framework for Implementation Research (CFIR) is a 'meta-theoretical' framework that includes a list of 26 validated constructs that can be used to explore what works and doesn't work and why in various contexts (<a href="http://cfirguide.org/constructs.html">http://cfirguide.org/constructs.html</a>). The CFIR is organized by five major domains: intervention, outer and inner setting, individuals involved, and process. Use of this framework enables us to systematically identify those components that are key to successful implementation of a multidisciplinary set of health interventions integral to TG health care.

We have applied the CFIR to the evaluation of the development of a comprehensive Center of Excellence for TG health care called the Gender Wellness Center (GWC), staffed by a multidisciplinary team who provide care to TG youth and adults. This presentation will describe how CFIR constructs were adapted to evaluate the GWC: **Individuals:** RWJ clinical scholars training, annual patient quality of life surveys (Child Health Questionnaire and SF-36v2), cultural competency training and student mentoring; **Intervention**: GAP analysis, participatory logic modeling for each service line (medical, surgical and behavioral), strategic planning; **Outer Setting**: creation of TG advisory board, needs assessment of TG health care disparities, patient and family focus groups to validate published needs assessments for TG health; **Inner setting**: cultural and clinical competency training for hospital and clinic staff; **Implementation Process:** incorporation of World Professional Association for Transgender Health (WPATH) standards of care, electronic medical record upgrade, periodic medical record reviews and creation of a pediatric patient registry.

# **References:**

Damschroder, L. J., & Lowery, J. C. (2013). Evaluation of a large-scale weight management program using the consolidated framework for implementation research (CFIR). Implementation Science, 8, 51.

Damschroder, L., Aron, D., Keith, R., Kirsh, S., Alexander, J., & Lowery, J. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implementation Science, 4(1), 50.

# APPENDIX J: EVALUATION AND OTHER RESOURCES

For more resources, click to visit the Google Drive with access to more files.