
Central Brooklyn Health Movement

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A Movement BY and FOR the PEOPLE

Developing and Testing a Model for Urban Healthcare Reform
in the
United States of America:
Access, Equity, Better Health and Quality of Life
at
Sustainable Cost

A Prospectus

January 8, 2018

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Central Brooklyn Better Health Movement

I. The Problem:

a. General Background

The healthcare system of the United States of America has features that make it the best in the world, but still other characteristics that are not so positive. First of all, it is the most expensive in the world, taking up almost 18% of the Gross Domestic Product (GDP). Its cost is increasing as well such that in 2015, U.S, healthcare spending rose by 5.8%, reaching 3.2 trillion dollars. What this means in individual terms is a per-person healthcare cost of $9,990 or $40,000 for a family of four annually. Despite that enormous and unsustainable expenditure, U.S. life expectancy is ranked by the World Health Organization (WHO) as only 31st out of that of its 194 member countries and 43rd by the United Nations rankings. Life expectancy is not the only one issue. With regard to performance of the system, WHO's ranking places the U.S. system as only 37th out of those same 194 countries. Among the developed countries of the world, the Organization for Economic Cooperation and Development (OECD) places the U.S. healthcare system as dead last or 11th out of 11.

Why is this so? There are many reasons for the problems of the U.S. healthcare system. First of all, it is not a unified system. Based on free-market principles, there are, in fact, multiple systems, fragments of systems, and non-systems, both for the delivery of services as well as for the payment for those services. In many cases, the systems and payors are in competition with each other. In others, they unite, even if unofficially, to block change. There are private payors in the form of the commercial insurers and the public themselves and public payors in the form of federal and state governmental reimbursement actors in Medicare and Medicaid, as well as other governmental agencies, including the Veterans Administration. Payment or reimbursement types and requirements for services provided is also complex. The large insurers may require approvals prior to procedures or hospitalizations. If such is not obtained, refusal to cover the costs follows. For Medicare and Medicaid, fee-for-service is giving way increasingly to pay-for performance and quality- or outcome-indexed reimbursement for physician and other health professional services. The regulations are complex and not necessarily easy with which to be in compliance, and penalties, as well as incentive bonus payments add to the complexity.

Beyond the payor issues, there are many providers that range from the large commercial and not-for-profit provider systems to group practices of varying range including primary care, as well as specialties, and the shrinking, but still important, pool of individual medical practices. Communication among the many types of providers, institutional and individual, is still poor, despite the advent of the electronic medical record and the plan for health information exchanges to improve this essential part of the overall process. The extent of this problem is evident when one considers the individual with a complex, multiple co-

morbidity illness, such as end-stage renal disease. Such an individual is likely to have as many as six or more physicians caring for him or her. This could include a primary care physician, nephrologist, endocrinologist, cardiologist, vascular access surgeon, gastroenterologist, neurologist, dermatologist, psychiatrist, palliative care specialist, podiatrist, and one or more Nurse Practitioners, not to mention a dietician/nutritionist, and a social worker. Multiple medications and other diagnostic and therapeutic modalities are prescribed, again often without coordination and attention to conflicting interactions and/or therapeutic priorities. Wasteful redundancy is more the norm than anything else. The typical patient has little understanding of what is being done, including the prescribed medications, which may not be economically feasible or taken because their importance is not understood or simply ignored. Under these circumstances, for many individuals, the Emergency Room of the local hospital becomes, of necessity, the place to go when problems arise need sorting out. It is not hard to see why fragmentation of care is the norm, rather than what it should or could be under a truly unified (and, some would argue, single-payor system).

To be added to the above mix of problems within the U.S. healthcare system (or lack thereof) are unequal access because of insurance problems and/or lack of adequate coverage; geographical or physical barriers; or a lack of knowledge or understanding; wasteful, often duplicative testing; medication use, redundancy, errors and harm; lack of true primary care that coordinates all the other specialty care; and, finally and most importantly, a lack of preventive care and attention to the individual's and his/her family's overall quality of life. Mental and behavioral health care, which is a critical element in health and even more so in the case of chronic illness, is inadequate, and even lacking, throughout the "system."

b. The Specific Challenge

Clearly, the state of U.S. health care is not acceptable. This is not news, and efforts to reform it in meaningful ways from many quarters have been underway for at least the past fifty tears. The Patient Protection and Affordable Care Act (aka "Obamacare"), enacted into law in March 2010, is the latest major effort in this regard, and, among other things, it has succeeded in extending healthcare coverage to many millions more of Americans, reducing the uncovered to the lowest levels ever. The Affordable Care Act, however flawed, has been a step in the right direction. All agree that much more needs to be done. The costs of U.S. health care are not sustainable, and the outcomes of the care that is provided remain far below what they should be. The biggest challenge facing U.S. health care (as well as the healthcare systems of most nations today is the problem of complex, multiple co-morbidities.

What can be done to improve the situation? This document proposes a specific model that can be implemented to address key elements of the problem and also evaluate a series of solutions to them, including the elements of health promotion and disease prevention. It is centered on the problem of chronic kidney disease (including End-Stage Renal Disease, ESRD) with its multiple co-morbidities; high mortality; loss of productivity and quality of life; and cost (up to 17% of the total Medicare budget for CKD and ESRD together, and 7% of the Medicare budget for ESRD despite the ESRD populations only being 1% of the Medicare population).

The hypothesis to be tested is whether a comprehensive model for the prevention, as well as better integrated management and care for people with CKD and ESRD, launched in a low-resource urban community with poor health indices and a high chronic disease burden can be shown to reduce the risk factors for kidney disease (diabetes and hypertension specifically), improve health outcomes related to renal disease, improve quality of life for those with CKD and ESRD, and reduce costs of care.

II. The Solution:

a. The Specific Example of Chronic and End-Stage Kidney Disease: Why Focus on It?

Chronic Kidney Disease (CKD) is a public health problem with wide-ranging societal effects. One in three adults is at risk for developing kidney disease, and 15% of the American population— some forty-five million people—are currently affected by some degree of CKD. Because there are often no symptoms, most people do not know they have CKD. Specifically, nearly half (48%) of all adults living with late-stage (Stages 3, 4 and 5) kidney disease, but not on dialysis, and 96% of people with early-stage (Stages 1 and 2) disease are not aware that they have problems with their kidney function[1]. Five percent of the patients with late-stage disease progress to Stage 5, End-Stage Renal Disease (ESRD), and require renal replacement therapy each year

Those with ESRD must either start dialysis or, if they are fortunate enough to have a living or deceased kidney donor who is an immunological match, get a kidney transplant. A kidney transplant is the preferred option for ESRD patients for many reasons. It offers better quality of life – patients feel better and do not have to endure the four-hour three-times-per-week dialysis treatments in order to stay alive. It is also less costly. In 2015, the Per Person Per Year (PPPY) cost of care for a hemodialysis patient $88,195. In contrast, the PPPY cost for a kidney transplant was $34,084[2]. Yet, waiting lists for a kidney are long - over 100,000 people (10,000 in New York, alone) and 20% of these individuals die waiting for a kidney[3]. Increasing awareness of the importance and benefits of kidney donation is critical to try to shorten the waiting list.

Kidney disease has several features that make it ideal for the model that is proposed in this document. First of all, kidney disease is incredibly expensive. As already stated, chronic kidney disease (including End-Stage Renal Disease, ESRD) is incredibly expensive with its multiple co-morbidities; high mortality; loss of productivity and quality of life; and cost (up to 17% of the total Medicare budget for CKD and ESRD together, and 7% of the Medicare budget for ESRD despite the ESRD populations only being 1% of the Medicare population). The PPPY costs in the paragraph above serve to emphasize that. Even kidney transplantation is not inexpensive and the immunosuppressive medications it requires for the life of the individual with the transplant are costly on an ongoing basis.

Such figures, however, do not tell the whole story of "cost." First of all, rarely mentioned is the fact that the vast majority of individuals with chronic kidney disease do live beyond Stage 3, dying of cardiovascular disease as a complication of diabetes and/or poorly

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[1] https://www.cdc.gov/diabetes/pubs/pdf/kidney_factsheet.pdf

[2] Healthcare Expenditures for Persons with ESRD, United States Renal Data System, 2017, https://www.usrds.org/2017/view/v2_09.aspx

[3] United Network for Organ Sharing, unos.org

controlled blood pressure. The tremendous cost of that has not been calculated, both in terms of care costs, but also loss of productivity and quality of life. Secondly, for those with chronic or end-stage renal disease, the "costs" of the accompanying mental health problems, and loss of productivity, have never been calculated. The "costs" to families are an important element of this, but again are difficult to estimate. The point is clear.

A second major feature of kidney disease is that it develops over a long period of time in most cases. What this means is that there are multiple points of intervention to prevent disease and/or detect it earlier so that its progression can be slowed or stopped. It is also true that the major risk factors for kidney disease are diabetes and hypertension, both of which can be addressed and reduced as risk factors. In fact, what we are talking about in terms of diabetes (overwhelmingly of the Type 2 variety) and hypertension are diseases that depend to a great degree on life style, including both nutrition and physical activity. Consistent with this, the Centers for Disease Control and Prevention in Atlanta estimates that 80% of all heart disease, kidney disease, stroke and Type 2 diabetes, as well as more than 40% of all cancers could be prevented if Americans would improve their nutrition, exercise regularly and avoid tobacco and excess alcohol[4]. Yet, out of the $9,990 per person spent on medical care in the U.S per year, only $251 is spent on health promotion and disease prevention[5,6]. The message is clear: health promotion and prevention of disease must be elements of any new health and healthcare model – and in no case is it more true than it is for kidney disease. Although increasing the awareness of kidney donation/transplant to reduce the cost of caring for patients with ESRD and help them live the best life possible is important, ultimately the best way to reduce the costs of kidney disease is to prevent it altogether. We need to do all these things in a truly integrated approach to kidney disease that improves for outcomes and quality of life, while they also reduce costs.

A third important feature of kidney disease is that we have treatments for all stages of the disease, including replacement of failed kidney function. We can prevent the disease by reducing the risk factors for diabetes and hypertension, as well as obesity. Education, community mobilization, improved access to healthy foods, and provision for regular and effective physical activity are among those tools. Once diseases such as diabetes and hypertension are diagnosed, we can treat them with medications, as well as the health promoting activities just listed. With renal failure, we have both dialysis and kidney transplantation to offer. Reducing the need for either type of renal replacement therapy, as well as the mortality that occurs by the time an individual reaches Stage 3 kidney disease can all be used a measure of the degree of success over the long term of whatever integrated all-stage care model that we put in place. CKD and ESRD provide an optimal situation for the testing of a new, truly integrated approach to health care that begins with health promotion and continues on through the stages of kidney disease to kidney failure,

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[4] *The Power of prevention: chronic disease … the public health challenge of the 21st century*. (2009). Atlanta, GA: National Center for Chronic Disease Prevention and Health Promotion

[5] https://www.cdc.gov/nchs/fastats/health-expenditures.htm

[6] IOM (Institute of Medicine). 2012. For the Public's Health: Investing in a Healthier Future. Washington, DC: The National Academies Press

allowing us to test the multiple interventions, and types of interventions, that will truly make a difference in the health of the people we serve.

b. The Place

If kidney disease provides an optimal model for the implementation and testing of a new, truly integrated approach to health care across the spectrum from good health to organ failure and replacement of function, the next question is where to launch such a model?

The communities of Brownsville (BV) and East New York (ENY) in the Borough of Brooklyn in New York City provide a special opportunity to implement and assess the proposed model – especially as it relates to an urban setting. These communities provide several key qualities for the model:

1) A population of roughly 270,000 people – adults and children – who are anxious to be mobilized to achieve better health and quality of life;

2) Health indices/statistics that need improvement: life expectancy that is 10 years less than it is for other parts of Brooklyn and Manhattan; infant mortality that is twice that of Brooklyn as a whole and eight times that of Manhattan's Upper East Side; a premature mortality rate that is twice that of Brooklyn and New York City as a whole and five times that of Manhattan's Financial District; diabetes statistics that 1 in every 6 adults are Type 2 diabetics; and the top ten causes of death are higher in every category than those of New York City as a whole (NYCDOHMH Vital Statistics, 2015);

3) Far less than optimal access to health promotion and health care services;

4) Less-than-optimal social determinants of health that contribute to unacceptable health and quality of life statistics with a high burden of kidney disease and its risk factors.

Importantly, The Rogosin Institute has a new Center for an integrative approach to kidney care located in ENY so that both education, early diagnosis and care across the spectrum of kidney disease can be provided, both by the Center itself and its multiple partners in these two communities.

c. The Model/Solution

In 2016 The Rogosin Institute, together with local community leadership in Brownsville and East NY, launched The Central Brooklyn Better Health Movement (CBHM). At the center of this local leadership are DeCosta and Kimberly Headley, a father-daughter team, who have long-standing and extensive contacts in this community. DeCosta Headley himself spent 18 years representing the East New York-Brownsville area in the New York State Legislature. CBHM is a model that engages individuals, families and communities to assume more responsibility for their own well-being, empowering them to become part of the solution to achieve improved health. Rogosin's existing partnerships with community and faith-based leaders has led to the creation of a core group of volunteers who recognize the health challenges they and their neighbors are facing, and are in the best position to help bring about needed health changes in that community. These volunteers conduct outreach and health education throughout Central Brooklyn as part of the better health movement. Although the CBHM is a multi-sectoral approach, we are currently implementing a three-pronged tactical strategy that involves: 1) education programming in schools, 2) outreach in faith-based settings, and 3) alignment of partners to create a continuum of care. CBHM programming involves working with healthcare payors and providers such as Healthfirst, Brookdale Hospital, Interfaith Medical Center, Brownsville Multiservice Family Health Center, and organizations such as LiveOnNY and CAMBA. We are also exploring potential partnerships with organizations including the Brownsville Community Culinary Center, Make the Road New York, and Health People, as well as other non-profits and social service agencies working in Central Brooklyn. Endorsement of the CBHM from local government, congressional district leaders, and community leaders is also important to ensure success of the health movement. Rogosin's Problem Solving for Better Health® methodology (PSBH®) will be threaded through all of the community and school based activities.

1. CBHM in Schools

Because habits are formed when people are young, the CBHM is working with middle and high school students to reduce the incidence of CKD in the next generation. The school-based health education empowers and engages middle and high school students to create projects of their own design to get the word out about the importance of healthy living, healthy diets, what causes kidney disease, and how to prevent it. Young people have powerful voices that can be used to influence their peers and have impact on the behavior of the adults in their lives. During the 2016-2017 school year, a middle school health council and health education program was developed and piloted at Kappa V Middle School in Brownsville. Building on the success of the initial pilot, school-based programming will be expanded to occur in three middle schools: **Kappa V Middle School, Brownsville Collaborative, and The Greg Jackson School (IS/PS 284).** The program will be designed as an afterschool activity with oversight from leaders within the Health and Science departments. Activities will include cooking demonstrations, visits to the grocery store to

read food labels, and healthy meal planning (including a budget). Rewards and merit systems will be threaded into the program to increase student participation (computer labs, new library books etc.). CBHM will also engage college students from **Medgar Evers, CUNY School for Professional Studies, and Antioch College** nursing and social work programs as near-peer facilitators and messengers in all of our health promotion and educational programming, in schools and beyond to other community sites. Incentives for college student and community participation and leadership include scholarship awards, computer labs in the housing development, and course work credit (capstone projects).

2. CBHM in Faith-Based Settings

If more Pastors and other faith-based leaders deliver "better health" messages we believe we will have a better chance of transformational change in the community because congregants trust their leaders in faith. **Four churches in Central Brooklyn were identified for the faith based approach to pilot test the model. The churches include: Hebron Baptist Church, Berean Baptist Church, Grace Baptist Church, and Antioch Baptist Church.** Approximately 25 Congregants from these churches recently completed an 8-week Diabetes Self-Management Series delivered by Healthfirst (insurer) which will be followed by a PSBH workshop. The goal of the PSBH Program is to generate individual and group action plans to spread the newly learned "better health" messaging and mobilize more individuals to assume more self-care. Additionally, by partnering with organizations such as LiveOnNY, we can place tools into the hands of the faith based leaders and congregants regarding the importance of organ donation so that kidney transplant becomes a more feasible option for those that need it in New York (current wait list in NYC 6-8 years).

3. CBHM and Partnership Alignment

While community leaders work to increase engagement with schools and faith-based settings, Rogosin team members will work simultaneously to align partners to create a continuum of care to support people living with chronic illness. Through these efforts, Rogosin will connect with local primary care providers, hospitals, clinics, and nephrologists to identify patients at risk for developing CKD, and create pathways for patients with identified CKD. This will entail mobilizing healthcare providers and connecting community based organizations addressing health and creating a referral and tracking system. We are exploring partnering with PwC to utilize their DoubleJump Interchange model to refer and track program participants and look at population health measures.

4. Goals and Objectives/Measures

- Increase awareness of CKD (and Chronic Illness more broadly) in Central Brooklyn
- Screening and Early Detection of CKD in Central Brooklyn
- Increase Organ Donation in Brooklyn
- Partner with neighboring hospitals, healthcare facilities, social service agencies, local businesses, public officials, schools (all sectors) to build a comprehensive and collaborative strategy to improve health
- Involve community leaders, religious leaders and places of worship in the goal to improve health
- Engage congregation members and community leaders as messengers so health information is being disseminated by family, friends and trusted people in the community
- Include students as an active part of community-based change for better health to impact their peers, neighbors and their family members
- Demonstrate that this new model of community engagement in health promotion and disease prevention is sustainable and replicable
- Engage with local Congressional leaders, government officials, public policy about the current kidney related healthcare bills so that we are working together to ensure better health care access and delivery for all residents in Brooklyn and beyond

5. Expected Outcomes

- 100 community-based volunteers enlisted as core CBHM Messengers/Implementers
- 10,000 community members surveyed on their attitudes and awareness of kidney disease, transplant, and organ donation and reached with education information about kidney disease (including organ donation) CKD prevention and risk factors (year one, already achieved)
- Reach 1 million residents with health information (CKD prevention and risk factors) by end of 2018 through health education programming, distribution of health promotion materials, and engagement with social media and news outlets
- Identify individuals who are most at risk for kidney disease based on their survey answers Referral to a GP or nephrologist will be recommended and a list of doctors in the area will be distributed. (CKD screening for 75,000 residents)
- With regular encouragement from, and follow-up by, our volunteers, we estimate that 50% will actually make and keep appointments with a physician for follow-up
- Increase percent of population registered to be organ donors in Brooklyn

6. Project Activities and Priorities

Completed:

- General
  - Community survey of 10,000 residents conducted in summer and fall 2016 about attitudes and awareness of kidney disease, organ donation, and transplant.
  - Rogosin Brooklyn East Kidney Care and Education Center (2372 Linden Blvd) opened with dialysis center and community education space. Opening reception and ribbon cutting event held May 12, 2017 with 226 attendees, including local, state, and federal government representatives.
  - Education programming held in Mezzanine level of Rogosin Brooklyn East, including a Transplant Education program in June 2017, a Healthy Youth Program in August 2017, and an 8-week Diabetes Self-Management from October-December 2017.
- CBHM in Schools
  - School health program and curriculum developed and piloted at Kappa V Middle School in Brownsville during 2016-2017 school year.
- CBHM in Faith-based Settings
  - PSBH introduced to faith-based leaders at Hebron Baptist Church in March 2017 and to faith-based leaders from multiple area churches in December 2017.
- CBHM and Partnership Alignment
  - Relationship with Brooklyn Borough President's office strengthened through participation in BP organized community health events during spring and summer 2017, as well as Crochet for a Cause partnership through participation in the kick-off at Brooklyn Borough Hall in March 2017, and hosting the wrap-up press conference event at Rogosin Brooklyn East in November 2017.
  - Began conversations with PwC about DoubleJump Interchange program and potential opportunities for collaboration.
  - Joined Healthfirst Healthy Village Clinical Advisory Board.

7. Proposed Future Activities

- General
  - Determine opportunities for collaboration with/replication of China CKD program. Translate China CKD survey to English and determine need for IRB application, team for collecting survey data, and survey collection processes.
  - Develop public health messaging campaign on chronic disease prevention for dissemination through social media and other media platforms/news outlets.
- CBHM in Schools
  - Train cadre of college/grad students (Medgar Evers, Antioch College) to carry out youth education and school health council PSBH program afterschool for students and parent coordinators at Kappa V, Brownsville Collaborative, and IS/PS 284.
- CBHM in Faith-based Settings
  - In partnership with LiveOn NY, develop a collaborative project to increase awareness of organ donation and percent of population registered to be organ donors. Implementing a series of "Kidney Sundays" events at churches and incorporating organ donation education, organ donor and transplant recipient testimonials, and organ donation registration drives. Submit grant to LiveOn NY Foundation to develop and implement program. Goal: 30% of Brooklyn residents registered by end of 2018 (vs 20.07% in Kings now)
  - Conduct PSBH workshop with faith-based leaders from Diabetes Self-Management Program in January 2018 and with subsequent faith-based groups throughout 2018.
- CBHM and Partnership Alignment
  - Engage with city, state, and federal legislators, including Kirsten Gillibrand, Chuck Schumer, Orrin Hatch, Ron Wyden, Hakeem Jeffries, Latrice Walker, Nikki Lucas, and with entities such as CMS/CMMI, AAKP, the Brooklyn Chamber of Commerce, Lions Club, Council of Retired Supervisors and Administrators, NYS Black and Puerto Rican Legislative Caucus. Follow up on previous meeting with Senator Jesse Hamilton's office (2016) to determine how best to utilize his 27,000-newsletter audience.
  - Set up meetings to determine potential collaboration opportunities with organizations such as MJHS Elderplan, PCDC, Make the Road New York, Health People, and Brownsville Community Culinary Center, and strengthen existing relationships with CAMBA, Brownsville Multiservice Family Health Center, One Brooklyn Health System, Healthfirst, Caremore, NADAP, and MJHS.
  - Outreach to primary care providers, hospitals, and clinics (Bishop Walker and others) to build relationships and determine pathways for referral and CKD screening.
  - Continue conversations with PwC (and other integrative tech initiatives) to determine feasibility of utilizing DoubleJump Interchange program (or other platforms) to screen, track referrals, and follow-up in the Brooklyn pilot program.

III. Summary:

The bottom line is that the **Central Brooklyn Health Movement** (**CBHM**) presents critically important opportunities:

1. To demonstrate the power and ability of the **people themselves (residents of Brownsville and East New York in particular)**, in concert with professional healthcare providers and organizations, **to create and test a model of better health** that is driven by the people themselves as the critical, active core of the model. Such a model will be capable of **promoting good health and lifestyle habits, improving health indices** (including diabetes, obesity and hypertensions, as well as those specifically related to kidney disease), **and quality of life for all residents equitably and justly**. It will also be both **cost-effective and sustainable.**

2. In accomplishing what is described in Item #1 above, to demonstrate the key principle for U.S. healthcare reform and the achievement of a just and equitable healthcare system for everyone that –

The people with the (health and other) problems are not the problem. Rather, they are the solution!!

3. Based on the expected positive results of the implementation and evaluation of the CBHM model proposed here, **recommend its replication, adjusted to local conditions as necessary, in urban communities across the United States.**

This is tremendous challenge, but it is the belief of those who, together, are encouraging and supporting this effort that, because of the good people of Brownsville and East New York, it will be successful. It will demonstrate to the rest of the U.S. just who and what these people are – the very best of America!!