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Community Engaged Research



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3 | In this Issue

*Omar A. Khan, M.D., M.H.S.,
Timothy E. Gibbs, M.P.H., N.P.Mc.*

4 | Why CEnR matters for
Health Equity

*Heather Bittner Fagan, M.D., M.P.H.,
F.A.A.F.P.,
Jacqueline Ortiz, M. Phil.,
Bettina Twardy Riveros, Esq.*

8 | Realizing Collective Impact
for Community Health: A
Wilmington Case Study

*Allison Karpyn, Ph.D.,
Henry Wolgast, Tara Tracy*

14 | Firearm Violence
in Wilmington

David Chen, M.D., M.P.H.

24 | Assessing Delaware Parents'
Knowledge, Attitudes
and Preferences About
Long Acting Reversible
Contraceptives for Teens
Using Participatory Action
Research

*Krishna White, M.D., M.P.H.,
Jane Bowen, M.H.S., Aniah Coley, M.S.,
Alexis Marvel, B.S.N., R.N.,
Jessica Walters, M.D.,
Sarah Vater, M.D.,
Jennette Fennimore, Andrea Miller*

32 | Addressing the Sexual
Health of Delaware Teens
through Evidence-Based
and Promising Education

*Christopher C. Moore, B.A., LSSGB
Nicole A. Fournakis, B.S.*

38 | Global Health Matters

Fogarty International Center

50 | PreparednessBuddy
Initiative Helps Vulnerable
Delawareans Prepare for
Emergencies

*Sean Dooley, Community Relations Officer,
Delaware Division of Public Health*

52 | Increasing Access to
Empirically-Validated
Interventions for Autism
Spectrum Disorder:
Dissemination of PEERS
into Community Health
Settings

*Laura Dewey, Ph.D.,
Cathy Rose, L.P.C.M.H.,
Jessica Mueller, Psy.D.,
Brianna Spencer, B.A.,
Brian Freedman, Ph.D.*

62 | A Stroke Reduction Health
Plan for Older Adults
in Rural Sussex County,
Delaware

*Stacey Novello, B.S.N., R.N., C.C.R.N.,
Mary Elizabeth Bowen, Ph.D.,
Mari Griffioen, Ph.D., R.N.*

70 | Screening Wilmington
Communities through the
Blood Pressure Ambassador
Program

*Dominique Medaglio, Pharm.D., M.S.,
Candyce Norris, B.S., Jamila Davis, B.S.*

76 | Expanding care for
patients infected with
Hepatitis C through
community partnership
in Delaware

*Deborah Kahal, M.D.,
Neal D. Goldstein, Ph.D., M.B.B.,
Arlene Bincsik, R.N., Tom Stephens, M.D.,
Karla Testa, M.D.,
Susan Szabo, M.D.*

80 | Community Engaged
Research: Lexicon of Terms82 | Community Engaged
Research: Resources

86 | Index of Advertisers

**COVER**

The cover image symbolizes the interconnections patients and other healthcare stakeholders have as equitable partners—as opposed to research subjects—who leverage their lived experience and expertise to influence

research to be more patient centered, relevant, and useful. Their early and continued involvement throughout a study can lead to greater use and uptake of research results by patients and stakeholders within the healthcare community. This is the foundation of Community Engaged Research.

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IN THIS ISSUE



Omar A. Khan, M.D., M.H.S.
President



Timothy E. Gibbs, M.P.H., N.P.Mc.
Executive Director

Not so long ago, communities were to be ‘studied’ and perhaps ‘worked with’. We have fortunately entered an era where partnership with communities is much better understood and articulated. Community Engaged Research, CER (or sometimes CEnR) for short, considers and elevates the power of bringing- even welcoming- community partners into the traditional research process.

While CER is not the right fit for all research, it can be a powerful tool to better understand what is occurring in the social environment and with individual patients, with a view to determining better outcomes. In turn, CER can be an effective mechanism to cycle results back into the community with whom the research is being jointly investigated.

This issue is focused on CER, and the Academy/DPHA has been a proud partner in a CER partnership focused on Chronic Kidney Disease in Delaware. Through that partnership, we learned about what mattered to patients, and we developed a deeper level of compassion and understanding that traditional research might not have engendered.

CER doesn’t mean abandoning traditional research protocols and best practices, rather it adds dimension and perspective. During the CKD Stakeholder Engagement Initiative we had the good fortune to meet William “Bill” Murray. Bill died due to complications from heart disease toward the end of the official research protocol. Bill was a fighter, a champion, and an excellent man. He was a passionate advocate, a pillar of our group, and is sorely missed. We valued his ideas and how he was always energetic, and passionate- in other words, engaged.

Other CER studies in this issue focus on a range of topics, including: adolescent pregnancy, autism, curbing violence in the City of Wilmington, stroke reduction, community collective impact, LARC, and Hepatitis C.

We thank Heather Bittner Fagan, M.D., M.P.H., F.A.A.F.P. and Claudine Jurkovitz, M.D., M.P.H. for their guest editorship of this issue.

Since September of 2015 we have published this Journal and watched its readership grow. Along the way we’ve had the unintended but desirable consequence of bringing people and groups together around common themes who may otherwise never have collaborated. That is a good thing, and is now a part of our stated goal – collaboration on behalf of public health.

Every issue will likely feature articles which may not have an obvious context within the issue theme. The reality is that we want to elevate excellent work on behalf of our community when it occurs, rather than hold it back until a future issue where it would better “fit.” In keeping with peer-reviewed journals which feature theme issues with no more than half the articles of that theme, we will continue featuring the best of medicine and public health in each issue.

If you are engaged in the practice of public health education, prevention, or research please consider penning an article. To be sure, it is work on your part and on ours, but we engage together- as researchers, community members, practitioners- to improve the public’s health.



Why CEnR matters for Health Equity

*Heather Bittner Fagan, M.D., M.P.H., F.A.A.F.P,
Jacqueline Ortiz, M. Phil. and
Bettina Twardy Riveros, Esq.*

Community-Engaged Research (CEnR) has become the talk of the town in translational research. The National Institute of Health (NIH), the predominant funder of research in the United States, has made translational research a priority, and emphasizes community engagement as a necessary component of translational research. Translational research seeks to effectively translate new knowledge (research) into new approaches for prevention, diagnosis, and treatment of disease and translation is essential for improving health (impact). Initially, most of us defined translational research as "bench to bedside" but disparity science and implementation science has made us all acutely aware that we need to go much further than the bedside and ensure that the often amazing discoveries of science are effectively and equitably shared to the benefit of all communities. In this issue, we highlight several local examples of CEnR. To begin, Dr. Dewey's work and the work of Moore and colleagues are examples of implementation, taking evidence-based interventions and applying them in the real world settings where these interventions are needed most.

"The challenge associated with knitting investigators and stakeholders together in bidirectional relationships across the full spectrum of research activities is enormous"

Community-Engaged research (CEnR) is about partnership.

The ultimate goal of research is to improve health. Yet, research often fails to permeate locally, especially in vulnerable communities. CEnR is not a particular method but rather an approach to research which emphasizes an equitable partnership and seeks to include the voice of those communities who are likely to be impacted by the research. CEnR prioritizes developing capacity, improving trust, and translating knowledge to action. While CEnR is not exclusively about engaging with vulnerable populations, it is especially pertinent in communities who experience disparity. Dr. Kahal's work educating community physicians on Hepatitis C virus (HCV) screening and treatment is an example where the having done the science and created the medicine are not enough. Lifesaving treatments for HCV have often failed to get to the vulnerable communities who need it most.

Engaging patients and communities in research improves impact.

It seems obvious: engaging the target community in the research process increases the likelihood of success. Yet, organizations and individuals struggle with the practicality of how to do this. The typical recipe for research success includes highly focused research, centered on the priorities of the funder, led by a single investigator at an academic institution and designed to begin and end according to funding of a limited time frame. This recipe often opposes the need for shared power, responsiveness and transparency needed to truly partner with a community. And this recipe often fails to address many of the complex problems in health care and health inequity. In the academic world of "publish or perish," a researcher may prioritize publication yet publication is rarely a route to meaningful dissemination

and impact in the community. In CEnR, academics and communities collaborate and share a priority-to have a meaningful improvement of health.

Let's start somewhere

Although the terms CEnR and Community-based Participatory Research (CBPR) are used interchangeably, CEnR is an umbrella term which includes CBPR. CBPR includes the community as a full partner in all phases of research and is often considered highest level of CEnR, the holy grail of community engagement. Yet, most researchers are not CBPR researchers and most are not trained in CEnR. Yet, even investigator-driven research can and should embrace the principles and approaches of CEnR in order to improve research translation. A researcher can work with communities to identify outcomes which matter most to them, for example diabetics may care more about amputation rates than hemoglobin A1C blood test results. A researcher may be more successful in disseminating knowledge to the target community using lay language at a certain reading level as opposed to the highly technical jargon-rich language used in scientific journals and meetings. Sharing power and engaging the help at any point in the research process makes for better translational research. And translational research, that which applies discovery to improve the human condition, is the real Holy Grail we are all trying to grasp.

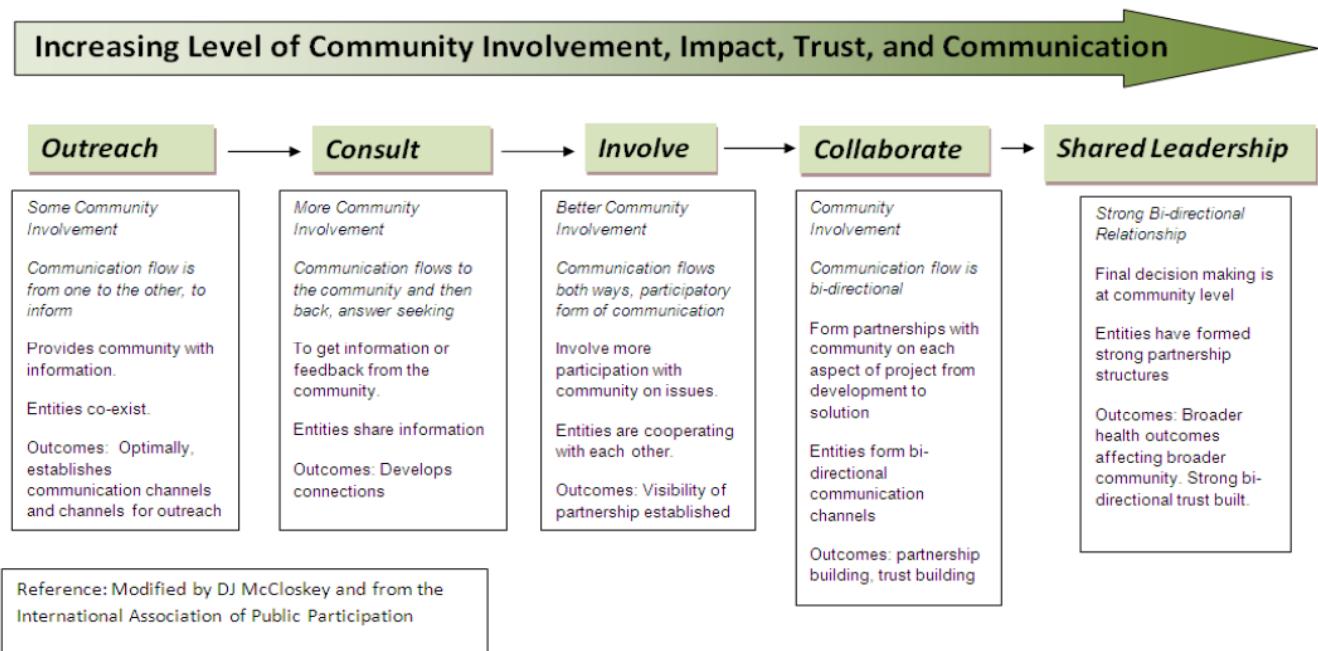
CEnR and its relation to Health Equity

Achieving health equity will require community engagement. Since the publication of the seminal report *Unequal Treatment* in 2003 there has been a steady increase in the volume of research dedicated to identifying and understanding disparities in health outcomes among underserved populations. We have learned through this body of work that disparities are the result of a complex interplay of factors including pressures from social determinants of health environment, individual behavior and the effects of institutionalized racism in the provision of care. The problem is well-documented. However, to translate that body of work into interventions that narrow the gap fundamentally requires the community to inform and guide the development and implementation of programs that will be most effective.

Community participation is specifically effective in ensuring interventions are locally and culturally relevant to a given populations. Often the underlying causes of patterns that lead to poor health outcomes are rooted in



Community Engagement Continuum



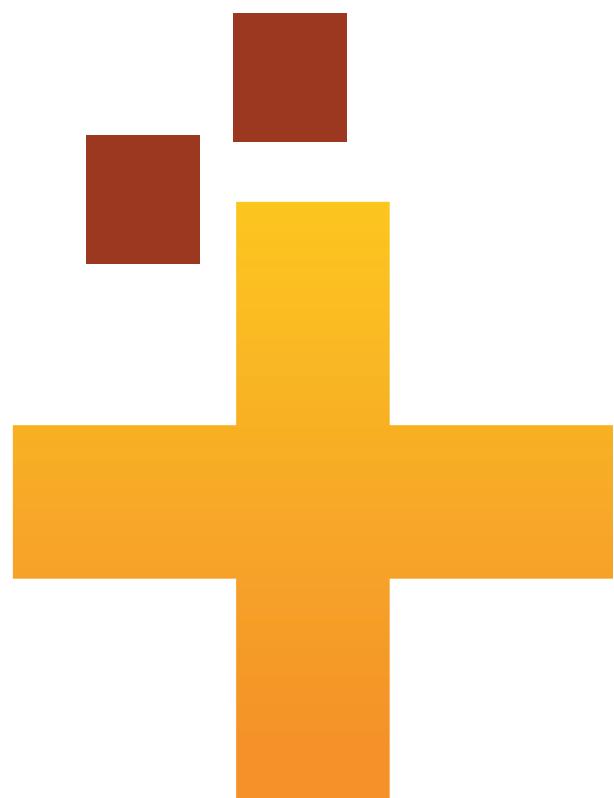
factors that are unique to place or patterns of interaction. Dr. Chen's work, featured in this issue, focuses on curbing violence in Wilmington; this work is a good example of engaging the community most affected by a problem to solve the problem and highlights the importance of understanding and addressing social determinants of a complex medical issue. As health care systems increasingly use community health workers to engage the community in health care and address the social determinants of health, the role of community health workers has been the subject of a great deal of research. In the work by Medaglio published in this edition, we see how, alongside other institutional supports, community health workers target specific barriers, address SDOH and help individuals to access needed medical resources.

Involving the community in research and intervention design leverages cultural norms and social relationships within the community, making what might have been a barrier a stepping stone to sustainable health improvement initiatives. The challenge is to form trusting relationships with community institutions that can be sustained over time, so that better health outcomes can be sustained. CEnR recognizes that collaboration and advocacy are needed to address health disparity. A number of challenges make sustaining relationships difficult, including the cyclical nature of grant funding coupled with shrinking public funding for community initiatives. In the end, the road to success in decreasing disparities and making long term sustainable improvements runs through community engagement. Listen to the community voice and switch the old

approach. It's not research **on** us or advocacy **for** us, it is research and advocacy **with** us. Engaging those who bear the burden of a problem not only makes good sense, it makes good science.

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A New Taxonomy for Stakeholder Engagement in Patient-Centered Outcomes Research
ACCEL: this figure was created with support from an Institutional Development Award (IDeA) from the National Institute of General Medical Sciences of the National Institute of Health under grant number U54-GM 104941 (PI: Binder-Macleod)





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Realizing Collective Impact for Community Health: A Wilmington Case Study

Allison Karpyn, Ph.D., Henry Wolgast and Tara Tracy

Abstract: As our state and nation face increasingly tight program budgets and more limited funding sources, collaboration has come to the forefront as a critical mechanism to promote health and well-being. The Collective Impact framework is an emerging approach to guide larger scale changes at a community or regional level. Through the establishment of 5 core tenants including establishing a backbone organization/central infrastructure, shared agenda, shared measurement systems, mutually reinforcing activities and continuous communication the CI framework advances the work of prior theorists and creates a foundation for health promotion. In this article we discuss the foundations of the approach and describe how the tenants are applied using examples from a case study of the Wilmington Collective Community Impact Study. Finally we reflect on the evidence to date for the CI approach and offer critical points of discussion to advance community-engaged programming in a small city.

Collective impact (CI) approaches are increasingly being used locally and globally to more efficiently and collaboratively address the need for large scale social change.^{1,2} The CI framework seeks to maximize available resources, both public and private, by bringing together what might otherwise be independent efforts. While strategies for collaboration, and an emphasis on community engagement is certainly not new in the fields of public health and community development, the CI framework provides a core infrastructure for collaboration.

The practice of community engagement is now well-established as part of large and small foundation funding efforts³⁻⁵, health promotion programming and research supported by the Centers for Disease Control and Prevention, Institute for Education Sciences and the National Institutes of Health⁶⁻¹⁰, among others. Such mechanisms build on tested theoretical frameworks with wide-spread application including Community-based Participatory Research¹¹, Theory of Collective Efficacy^{12,13} and Community Coalition Action Theory (CCAT)^{14,15}.

The CI method while originally developed by industry, largely advances the earlier work of Butterfoss and Kegler's CCAT but applies a 5 pillar framework. These pillars include partners coming together to define 1) a common agenda, 2) shared measurement, 3) mutually reinforcing activities and maintain 4) continuous communication, guided by an identified, strong 5) backbone organization. At the same time, the approach emphasizes the importance of advocacy, equity and supports a culture that fosters trust, respect, and regard for the local context.

Alignment is at the centerpiece of the CI model. In so doing it attempts to reduce or eliminate duplicative activities and achieve measures and programming which more intentionally address a problem across sectors, through coordination and sharing.

Despite its growing application and use, there remains few applied examples of the approach in the peer-reviewed literature¹⁶. Early examples from the grey

literature however demonstrate the impact that collective impact can have on underserved communities. For example, in 2011 the Campbell Soup Company made a \$10 million commitment to reduce hunger and obesity in the Camden, NJ community, the location of its World Headquarters¹⁷. The city of Camden is home to 74,500 residents, 32% of which are children, and 45% which speak a language other than English at home. Nearly 40% of its residents live in poverty making, on average, \$14,100 a year, per capita¹⁸. Yet, despite challenges, agencies including the YMCA, The Food Bank, Camden Coalition for Healthcare Providers, and The Food Trust committed resources to achieve strong programming and support services in the area guided by a Collective Impact Framework. Since this time a number of other funders and community leaders have joined the collective, further leveraging the common agenda for their own work.

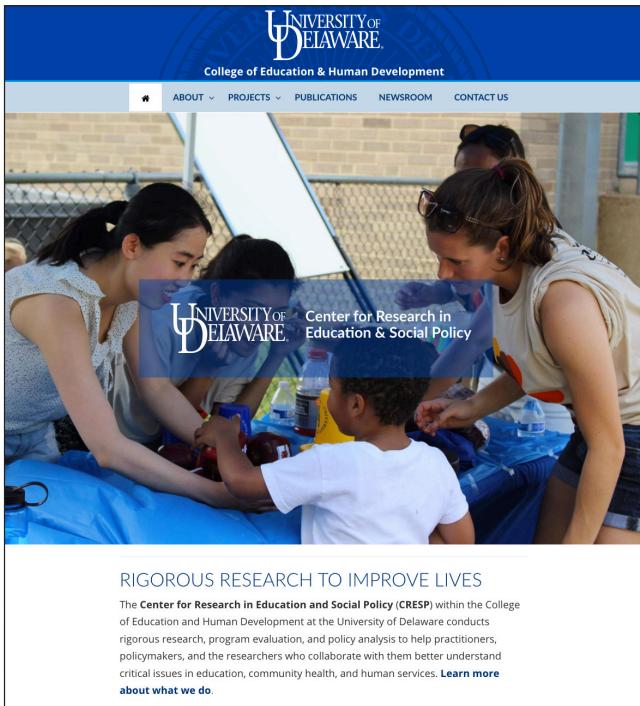
Here we describe the early phases of a Wilmington, DE model which is working to build a collective impact framework. In it we will describe how the 5 pillars of the collective impact model can work to promote healthy diets in a local community.

The Wilmington Context

The University of Delaware's Center for Research in Education and Social Policy (CRESP), although not based in the city of Wilmington, is committed to community engagement to support and address inequities faced by residents across the state. In 2018 the Center was awarded a USDA AFRI grant in order to pilot and test a collect impact approach to improving fruit and vegetable consumption on the west-side of Wilmington. The project, "Realizing a Community's Collective Impact" or CCI, sought to leverage existing efforts on the west-side of the city to test whether or not the collective could improve fruit and vegetable consumption. Wilmington is home to 71,000 residents, 25% of whom are children with a growing senior population (13%). Twenty-six percent of Wilmington residents live in poverty, with an average per capita income of \$26,263¹⁹.

Backbone Organization

Backbone organizations, defined as those that create and manage collective impact programs, require an organization with dedicated staff to manage the work of the collective¹. In Wilmington the decision to have CRESP serve as the backbone organization



was largely decided due to the financial support available for the project. In both, the backbone organization is responsible for ensuring activities are mutually reinforcing, that partners receive continuous communication, and that evaluation strategies are implemented in alignment with the goals of the collective.

- 1) a common agenda
- 2) shared measurement
- 3) mutually reinforcing activities and maintain
- 4) continuous communication

1. Common Agenda

There are a variety of resources available publicly to help organizations and projects develop a common agenda^{2,20} though all emphasize the importance of achieving common principals to guide the group and its decisions, a common understanding of the problem, a measurable goal to help define success (and how it is measured), a clear framework for how the collective will operate and how the group will split up the work, and an understanding for how progress will be tracked and lessons will be learned. Embedded

within these conversations the group is also encouraged to work within an asset-based (rather than deficit-based) approach, identify opportunities to achieve shared responsibility, emphasize the importance of empowerment for the collective and the community and to think holistically about health and community well-being. Other important tenants of the approach include transparency, achieving sustainable relationships and respectful communication.

2. Shared Measurement

Measurement strategies require use of common metrics, collectively agreed upon objectives, and partners willing to incorporate common measurement strategies and reporting format to benchmark results. While there is no one size fits all approach to changing the health of communities, it is possible to nest the work being done and set targets for improved outcomes. Metrics should include at minimum the size of the total investments including leveraged funding, the volume of community programming underway (time by activity and number of individuals impacted) as well as the behavioral outcomes resulting from programs including changes in knowledge, attitudes and behaviors relevant to each of the three categories of effort noted above. Three steps to the development of shared outcome measurement include Step 1: Identifying and Agreeing on Objectives, Step 2: Leveraging Existing Instruments and Approaches, and Step 3: Launching the Resources and Protocol (figure 1).

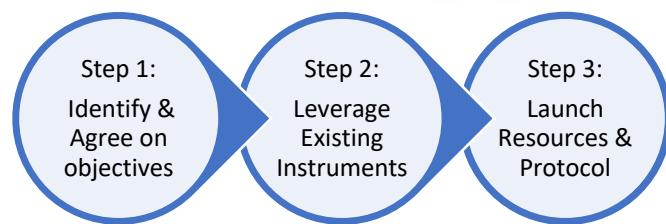


Figure 1. Creating Shared Outcome Measurement

Step 1: Identify & Agree on Objectives

Common objectives used in prior collective impact work include improving the quantity and quality of physical activity, improving the quality and diets of children, increasing awareness of the importance of physical activity, achieving meaningful and sustained parent involvement in schools and childrens' activities, creating a culture of support for eating well and exercising and effectively engaging community leaders. In the Wilmington example, partners recognized that families

did not consume the recommended servings of fruits and vegetables, and partners agreed that a core metric for impact of the intervention would be to measurably improve fruit and vegetable consumption.

Step 2: Leverage Existing Instruments

In order to understand the collective impact across stakeholder groups a review of existing instruments was undertaken by the backbone organization in consultation with the collective. Ultimately one tool which would be administered by the backbone itself was selected for community use. In other examples, however a set of questions, or indicator metrics have been identified which allows each organization to independently measure impacts using common wording such that data can be combined to report on the impact of the collective as a whole. Most typically impacts include output metrics including quantity of programming and participation, as well as outcome metrics such as change in physical activity, food insecurity, economic stability or similar. In addition, efforts to understand the total amount of funds invested and those that were leveraged as a result of the collective are often valuable. In the case of Wilmington measures included data collected from the collective programs as well as randomly sampled household outcome data collected from the community for which programming was intended to benefit. Because the CCI effort included a research component as well, additional data was collected from a control community in the nearby city of Bear, DE.

Furthermore, it is important to note that existing secondary data, that is data that is already being collected nationally, could be used strategically to leverage on-the-ground data collection approaches. For example, where mature and intense programming is occurring, examination of shifts in hunger or obesity or other national indicators relative to other, similar areas in the US could be considered. Depending on the scope of the initiative, leveraging existing, valid and reliable metrics can generate greater support in the academic community for understanding the impact of the work and, at the same time, may alleviate data collection stress on the ground. One potential resource for this type of data collection is the National Collaborative on Childhood Obesity Research (NCCOR). NCCOR has established a measures registry which catalogues existing survey measures and the reliability and validity information supporting their use.

3. Mutually Reinforcing Activities.

In Wilmington, the project, “Realizing a Community’s Collective Impact” or CCI, builds on the Wilmington, DE-based knowledge, experience, and presence of the staff and leaders of 11 non-profit and institutional partners. The effort draws on existing efforts of these community partners but aligns efforts around a common theme and purpose, to encourage consumption of fruits and vegetables, specifically tomatoes and apples. Specifically partners’ representatives implement their existing and on-going nutrition education and healthy living programs while at the same time tailoring the work to encourage consumption of these particular items during the same month, and overlaying an additional common evidence-based zoo-animal messaging campaign (“Tastimals”) as part of their work in both English and Spanish. The Tastimals animal characters were previously shown to positively influence healthy food choices (Karpyn, et al. 2017; Karpyn, et al. 2016) and through the common framework, a greater impact at the community level can be achieved. Some examples of how the collective can work within a common agenda (Tastimals and tomato/apple promotion) while leveraging existing resources between mutually enforcing activities include:

- SNAP-Ed cooking programs (Food Bank of Delaware);
- Inclusion with bagged tomato or apple patient give-aways (Westside Family Healthcare);
- Dissemination at an event for the Friends of Father Tucker Park (West Side Grows);
- Pick-up during Mobile Pantry events (St. Francis Hospital); and,
- Distribution by St. Francis Hospital and the Delaware Zoological Society (the Society supported the original Tastimals research) as part of the “Zoo WalkBy” held during the “Healthy Kids, Brighter Futures” event.



Prior to the CCI project, most partners were aware of the other partners and their activities, and had, in some cases, sporadically collaborated to deliver nutrition education programs. However, the CCI partnership has created new bonds among the various partners: for example, the Food Bank of Delaware now delivers nutrition education programs at both St. Francis Hospital and Westside Family Healthcare; these organizations had not formally worked together prior to the CCI project.

4. Continuous Communication.

In a time where many forms of work rely almost exclusively on email, texting, and other electronic forms of communication, CCI implementation occurs largely through frequent and regular forms of face-to-face contact. For example, in Wilmington CCI partners meet locally in person at a site hosted by a CCI partner. These approximately two-hour meetings have generated important and useful feedback to project leaders (e.g., regarding Tastimal design, or study timing), and established new working partnerships. Also, the two CCI partners (i.e., Woodlawn Library, Adams Fresh Grocer) that do not host active nutrition education programs are nonetheless important community focal points within the study area. As such, staff from the CCI lead organization visits these two sites weekly to deliver a range of CCI program materials for pick up by these partners' clients. During these visits, Library and Grocer staff provide information regarding those program materials that generated interest, how the materials were used, and other key points of feedback.

Notwithstanding personal contacts, CCI leaders and staff use email to update partners on key and timely points such as delivery of program materials. Also, an e-newsletter is used to regularly update CCI's Advisory Community which is comprised of the Wilmington area's key funders of and policy makers for nutrition education efforts.

Reflections and Conclusions

In smaller cities and communities like Wilmington, DE, a collective approach is increasingly needed; both our nation's fiscal climate and interest in cross-sector community-engaged research and programming require it.

Particularly in smaller geographic areas, non-profit, government and foundation efforts to improve health and well-being can result in overlapping efforts and unintentionally approaching the same partners with

similar asks from the same institutions. At the same time, smaller institutions may undertake very similar activities but without the benefit of common metrics or coordination in the approach such that the resources brought to bear are less robust than could be achieved collectively. Further, once a collective approach is established the framework provides a foundation from which additional efforts can build and grow. In its most robust form, the collective is then working to both achieve its own common agenda, and that agenda can become a backbone for extending the work to other investors, researchers, and collaborations from additional sectors.

Prior research on the CI approach emphasizes the importance of the backbone organization's leadership to provide an effective means of communication and staffing. A strong backbone, which ideally comes from a single organization, has been found to further the collective's credibility, outreach in terms of its range of contacts, and effective technical assistance to its partners¹⁶. The backbones effectiveness also lies in its ability to attract additional partners and share lessons learned²¹.

As efforts to expand university and hospital-based intervention and research continues to expand into the community, efforts to develop and sustain partnerships both with each other, and across sectors will be of increasing importance. Perhaps most importantly however, will be our efforts to sustain and engage community partners in these efforts. A collective impact framework for this work will support more intentional, collaborative and sustained efforts which can help shape effective policy while maintaining stable and ongoing data collection efforts which can further advocate for needed programs, and to assist in closing gaps in disparities.

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HEALTH CARE PROVIDERS

Research has shown that a lung cancer screening can save lives.

A low-dose CT scan has been proven to reduce mortality risk in smokers and former smokers by 20 percent. The screening:

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- Has been endorsed by the American Cancer Society, American Lung Association, and U.S. Preventive Services Task Force

Your patients should be screened if they:

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- Have smoked the equivalent of a pack a day for 30 or more years, or two packs a day for 15 or more years.
- Currently smoke or quit smoking within the last 15 years.

Talk to your patients who smoke or have smoked about the lung cancer screening. Or they can call (302) 754-5574 to have a screening nurse navigator schedule a screening for them.



Firearm Violence in Wilmington



David Chen, M.D., M.P.H.

Abstract: Firearm related assault injuries disproportionately affect young men of color related to a variety of social & ecological vulnerabilities. Delaware, and particularly the city of Wilmington, has experienced a disproportionately high number of these injuries, and this article follows the public health approach in defining the scope of the problem, establishing what is known about the pathophysiology and transmission of injury, describing the effectiveness of newer prevention programs in both public safety and public health, and highlighting important constraints and considerations for program evaluation and research.

many are likely to be injured again with one study finding a 44% recurrence rate and 20% mortality rate within 5 years. (Sims et al., 1989) There are few health disparities that are as profound; the American College of Surgeons Committee on Trauma (ACS COT) has plainly stated, “Violent intentional injury is the most poorly addressed public health problem in America” (Stewart, Kuhls, Rotondo, & Bulger, 2018, p. 282). However, understanding firearm violence in public health terms is both a novel and complex task. The Violence Prevention Alliance of the World Health Organization (2011) outlines a public health approach to violence in four steps that could be applied to Delaware:

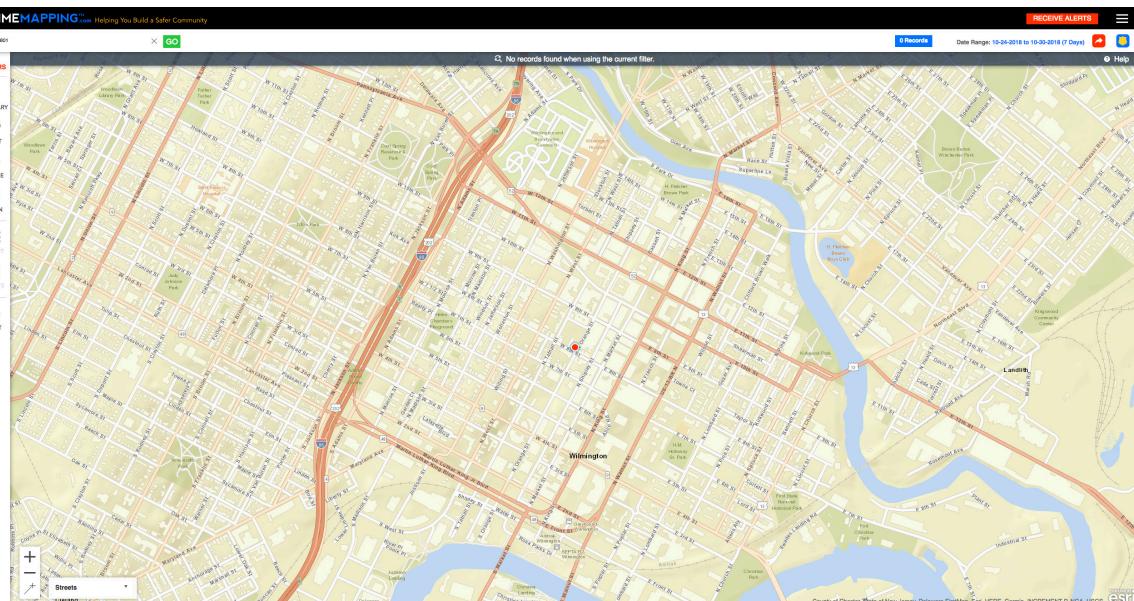
What is the role of public health in the prevention of violent firearm injuries? Homicide is the leading cause of death for young black Americans and those aged 10-34 years have died at more than 10 times the rate of white Americans (Sheats et al., 2018), mostly from firearm injuries (Centers for Disease Control [CDC], 2013). For those who survive their violent injuries, research suggests

1) Defining the problem

Wilmington’s experience with firearm violence is an outlier compared to the rest of the nation; a high profile article by Jones (2014) in Newsweek was literally titled “Murder Town USA (aka Wilmington, Delaware).” An epidemiologic investigation in Wilmington by the Centers for Disease Control and Prevention (2015)

notes “although Wilmington is a moderately-sized city of approximately 71,525 residents, when compared to all large cities in the United States, its homicide rate in recent years has been reported to be as high as 4th overall. In fact, in recent years, the growth in Delaware’s homicide rate (Wilmington is the largest city in Delaware) has outpaced that of every other state” (pp. 1-2). Adolescents 12-17 years old in Wilmington have a 3.4/1,000 risk of being a victim of firearm violence (compared to 1.8/1,000 in Chicago) making it the highest in the nation (Linderman, Horn, Para, & Fenn, 2017).

Public reporting on firearm violence in Delaware has improved recently. The Delaware News Journal maintains an online application to track publicly reported assault-related firearm injuries in Wilmington (“Wilmington Shootings,” 2018), and in 2018 the city of Wilmington began releasing reports on specific incidents through the online tool CrimeMapping (Read, 2018) as well as aggregate data comparing weekly crime reports to year-to-date historical trends



(“Compstat reports,” n.d.). Delaware received funding in 2016 to participate in the National Violent Death Reporting System (“State by State,” n.d.), a public health surveillance system meant to pool information from death certificates, coroner/medical examiners, law enforcement, and toxicology into an anonymous database (“National violent,” 2017).

But despite the increasing availability of public information on where and when specific incidents of firearm violence occur, some information is very difficult to obtain or never reliably tracked. Using healthcare information as an example, details about type

of weapon, caliber of bullet, and severity of injury may be documented in a trauma registry or police reports, but these are not accessible except for specific research objectives or only if aggregated to de-identify reporting. Circumstantial details (e.g. whether injury was caused by a fight or whether individuals were influenced by alcohol) may be documented as subjective historical data in a patient’s chart, but this depends on the initiative of individual providers. Patient medical records are often scattered among institutions and so determination of history of similar injuries or related health issues requires manually requesting and reviewing records, not all of which are available in the Delaware Health Information Network. Studies suggest as many as a third of assault-injured youth are uninsured (Cunningham et al., 2014) which would skew any analysis of administrative health insurance data attempting to assess broader utilization patterns. A primary care provider (PCP), who has the greatest liberty in accessing health records, might receive most of this health information, but even an astute PCP would not have default access to most social services or school data (such as from a guidance counselor suggesting recent conflicts there); they are not even routinely notified if their patient becomes incarcerated, related to the incident or not. Any health-related information is heavily protected under the Health Insurance Portability and Accountability Act (HIPAA) and cannot be shared with social service or justice systems without explicit and signed patient consent and is rarely subpoenaed.

Part of this data fragmentation is related to the “silos” in which different databases of information are stored (even within a single sector such as healthcare), but much of it also derives from the fact that while exposure to firearm violence is prevalent, events are both sparse and highly publicized. This makes it difficult for public information systems to disclose individual incident information while protecting anonymity to ensure victim safety. Systems may be reluctant to share information except on a case-by-case basis, and victims themselves may be unwilling to disclose the most pertinent incident details out of the very real fears that “snitches get stitches”, that they

may reveal self-incriminating information (especially if gang-affiliated), or that they will be forced to re-live an intensely traumatic experience (Parra, 2015).

What we can draw from public information and prior analyses of crime patterns (“Wilmington public safety strategies commission,” 2015) in the city of Wilmington are relatively simple conclusions: that firearm violence is clustered in several specific neighborhoods within the city (primarily with high rates of poverty) (Linderman et al., 2017) and is more likely to occur at certain times (night) and during certain months of the year (summer). Moreover, the community impact of firearm injury is difficult to overstate. The People’s Report, an ethnographic participatory action research study conducted by residents in Southbridge and Eastside communities, found that 60% of participants had “seen a seriously injured person after an incident of violence,” that 55% had at least one relative killed with a gun, that nearly 60% lost a friend to gun violence, and that the average age in which loss of a friend occurred was 18 years old (Payne, 2013, pp. 40-42).

In an interview for the News Journal, Dr. Hal Byck at Nemours Jessup Street office described his experiences as a pediatrician in a heavily affected community (the Northside) in this way:

“My purpose is not just to get them to 18 but to have them have a good foundation to get through life. So every time an 18- or 19-year-old is shot, not only does it hurt, but somewhere I didn’t do what I needed to do.” The Jessup Street office, which serves mostly Wilmington residents, deals with wellness visits and the average childhood struggles. But Byck’s team also takes on chronic stress and trauma, the kind associated with seeing a person shot to death outside your home or hearing gunshots regularly ring out down your block. Byck said about 25 to 30 percent of his childhood clients say they have seen someone get shot or die, a question he now asks as a part of childhood physicals. Some have seen this happen four or five times, he said.



For many who call Wilmington home, that’s just normal. (Horn, 2018)

2) Establish why violence occurs

The CDC promotes a social ecological framework in approaching violence prevention that recognizes that prevention must address individual, relationship, community, and societal factors (“The social ecological,” 2018). The investigation by the CDC in 2015, specific to Wilmington, attempted to characterize through a retrospective analysis of those who *perpetrated* a firearm crime what historical risk factors led to the incident (CDC, 2015). This found that a combination of factors, including prior victimization by violent crime and exposure to structural factors such as disconnection from socioeconomic support systems (e.g. through unemployment, incarceration, suspension/expulsion from the education system), was ultimately more predictive of *perpetration* than any single set of risk factors alone. What this confirms is that, for those living in poverty, structural inequity and disparity amplifies individual level risks of *victimization and perpetration*. This occurred even though the majority of these individuals had already received some form of social assistance program at some point (73%) with the majority having also been recipients of state juvenile services (such as community probation, residential detention, behavioral health services, or managed care services; 54%) (p. 6). It also suggests that those with the highest risks associated with violent injury, either as victim or as perpetrator, have poor integration with existing medical and social service supports.

On an intrapersonal level, exposure to violence is thought to create pathophysiologic biological and behavioral changes that increase vulnerability to maladaptive behaviors and poor health outcomes. In pediatrics and the study of child maltreatment, the proposed mechanism is that chronic environmental exposure to stressors (such as Adverse Childhood Events (ACEs), “toxic stress”, or allostatic load) eventually causes the hypothalamic-pituitary-adrenocortical (HPA) axis to become disordered (Shonkoff et al., 2012). This and other induced neurobiological changes impact development and are associated with abnormal immune system function (which predispose to medical illness and trauma) as well as changes in the frontal and limbic regions of the brain (which are responsible for emotional regulation and threat perception) (Moffitt & Tank, 2013). In the context of violent injury, this growing body of research has been adapted to propose

that repeated exposures to violence (such as through observation of abuse or by direct victimization) creates maladaptive biological and behavioral patterns over time which, if not treated, may eventually propagate to others through the perpetration of violent injury. Evidence does suggest that exposed children are more likely to carry weapons in adulthood (Casiano, Mota, Afifi, Enns, & Sareen, 2009) and that increased exposures to ACEs also increases risk for violence perpetration such as bullying, physical fighting, and dating violence as adolescents (Duke, Pettingell, McMorris, & Borowsky, 2010).

On an interpersonal level, person-to-person risk factors and expressions of violence propagate across relationships and social networks in patterns. Drs. Tracy, Braga, and Papachristos, the leading experts in firearm injury network analysis, summarize the relationships in this way:

The results of our systematic review demonstrate that one's risk of violence, including victimization and perpetration of gun or other weapon violence, is increased through close connection with someone who has either perpetrated or been a victim of violence, with transmission demonstrated across family ties, intimate partner relationships, peer networks, and co-offending networks. Although not restricted to studies specifically using measures of gun violence as exposures and outcomes, this review shows that serious weapon-related violence can potentially arise from exposure to domestic violence in childhood, not just from delinquent and criminal activity among peers. Furthermore, the introduction of weapon violence into an intimate partner relationship signifies an increased risk of severe subsequent violence in that relationship. (2016, p. 81)

In essence, the best studied interpersonal influences on weapon carrying behavior primarily involve three axes: family/home environment, peers, and co-offending networks. These clearly span community and societal domains, with focus on the latter two in the context of group violence (e.g. violence occurring in the context of gangs and gang affiliation). Innovative research in these networks using formal analysis found that in Boston 85% of all gunshot victims were in a single network representing less than 5% of the community's population (Papachristos & Wildeman, 2014), and that in Chicago nearly 70% of all nonfatal gun injuries were concentrated in a network representing only 6% of the total population (Papachristos, Wildeman, & Roberto,

2015). Non-gang members can still be at an elevated risk of firearm injury by "social closeness" rather than gang affiliation (Papachristos, Braga, & Piza, 2015), and some cities report lower rates of gang affiliation in adolescent assault injuries (Cunningham et al., 2014). Yet using predictive network analysis of co-offending networks to identify those at highest risk of injury is promising, and in Chicago a probabilistic "social contagion model" can identify individuals in a network at heightened imminent firearm injury risk on a real time basis (Green, Horel, & Papachristos, 2017).

The Delaware News Journal has reported closely on firearm violence and attributes numerous incidents to two specific groups, "Only My Brothers" and "Shoot to Kill", where dozens of members have been indicted since 2016 (Horn, Wilson, & Parra, 2018). According to claims by the Delaware Department of Justice: "Our prosecutors, working closely with law enforcement, have identified criminal street gangs as drivers of much of the violence in the city over the past several years."

3) Find out what works to prevent violence

Evidence from public safety studies increasingly show that punitive measures alone have limits to their effectiveness and that strategies more similar to public health which change the social & ecological environment will be necessary components in reducing violence. Public safety programs dealing with physical and social disorder, known as "disorder" or "broken windows" policing, can be effective in decreasing crime; a meta-analysis of 28 of these strategies in large and small geographic areas concluded there were "consistent crime reduction effects across a variety of violent, property, drug, and disorder outcome measures" (Braga, Welsh, & Schnell, 2015, p. 580). The effectiveness of these strategies, even though modest, are consistent and suggest that addressing issues of structural inequity (e.g. structural violence) and the ecological environment works. The conclusion of The People's Report, conducted in Southbridge and East Side, describe these relationships plainly but also highlights how guarded the community may be to increasing public safety presence:

Findings strongly suggest that physical violence in its many forms in Wilmington, Delaware is profoundly tied to structural inequality. A critical mass of residents reported direct and/or indirect experiences with violence in the form of: (1) physical assaults; (2) knifings; (3) shootings; (4) drug use/sales of drugs; and (5) homicide—to

more structural forms of violence including: (1) unemployment; (2) poor schooling opportunities; (3) unhealthy living conditions; or (4) “failing” or “corrupt” civic and political leadership. Also, a variant of residents spoke of “unfair” or invasive law enforcement procedures including being: (1) profiled and frisked; (2) caught up in raids or sweeps; (3) detained without detention; (4) arrested; and/or (5) incarcerated. Nonetheless, participants overall were found to demonstrate positively high levels of: (1) psychological well-being; (2) social well being; (3) attitudes toward education; (4) and attitudes toward employment. That is, while community residents reported being overwhelmed with physical violence as well as blocked opportunity or structural violence, these data strongly suggest that they love themselves; they love their communities and families; they want to work and; they want quality educational opportunities. (Payne, 2013, p. 25)

Here, the social determinants of health and public safety overlap and is where the fields can learn from each other. Both bodies of literature are comprised mostly of small studies with varying inclusion criteria, size, methods, quality, and interventions. This sort of heterogeneity can make it difficult to determine which programmatic elements are truly effective. As an example, programs that reduce juvenile recidivism vary widely and include everything from boot camps, cognitive-behavioral therapy, prison visitation, family therapy, drug court, victim-offender mediation, etc. with varying effectiveness; a meta-analytic overview by Lipsey (2016) suggested a novel approach to effectiveness research through “identification of factors that characterize the most effective programs” rather than the actual structure of programs themselves. (p. 126) His analysis concluded that “therapeutic” programs (e.g. counseling, mentoring, skills training, etc.) were more effective than those based on coercion/control (e.g. surveillance, deterrence, and discipline), and that among these the *quality* of the program perhaps mattered more than the actual *intervention* itself: “the average program of this rather variable generic sort can be quite effective if implemented well and targeted on high risk offenders. It does not take a magic bullet program to impact recidivism, only one that is well made and well aimed.” (p. 145)

This lesson, that the quality of a program may matter more than fidelity in replicating successful but specific models, is one that public health is also learning in

health behavior programming. It also gives hope that smaller cities and different environments can build successful programs *and* research. To that end, it will be instructive to consider several prototypes of successful models, drawing from both public safety and public health, to understand which elements can be best adopted in Wilmington.

Focused deterrence programs begin from the premise that a small number of individuals are responsible for the majority of firearm related violent incidents and that they respond to selective and strategic pressure (Braga & Weisburd, 2015). As David Kennedy (2006) describes, these programs identify key offenders and “communicate directly and repeatedly with offenders and groups to let them know (a) that they are under particular scrutiny, (b) which acts (such as shootings) will receive special attention, (c) when such attention has, in fact, been given to particular offenders and groups, and (d) what they can do to avoid enforcement action” (pp. 156-157). They are offered services and community supports, many of which can be provided by social service and health systems, but are reminded that firearm violence will result in special enforcement by “any and all legal tools” available to sanction groups (pp. 157). Most studies on focused deterrence found effectiveness in reducing youth homicides and violent crime in cities such as Boston, Cincinnati, Indianapolis, and Los Angeles (Braga & Weisburd, 2015). A number of these were necessarily quasi-experimental and Braga & Weisburd plainly state, “The positive outcomes of the existing body of evaluations indicate that additional randomized experimental evaluations, however difficult and costly, are warranted” (2015, p. 65).

By contrast, strictly non-punitive and popular healthcare programs for high-risk individuals are Hospital Violence Intervention Programs (HVIPs). These apply an intervention soon after a violent injury incident and couple it with intensive community-based case management. Promoted by the American College of Surgeons among many others, this approach seizes on the “teachable moment” created by violent injury to match patients to needed resources (Dicker et al., n.d.). Many programs use community health and outreach workers with personal prior experience with crime violence as the frontline engagement staff who can rapidly build rapport and serve as the bridge to connect patients to services. Programs have demonstrated effectiveness in reducing reinjury and hospital readmissions, reducing arrests and convictions for violent crime, and promoting employment (Purtle et al.,

2013; Chong et al., 2015). These programs are attractive because they avoid the involvement of law enforcement and focus on supportive rather than punitive or deterrent interventions.

The literature on HVIPs echo some of Lipsey's observations on juvenile recidivism, finding that the most effective programs maximize impact through peer counseling (Becker, Hall, Ursic, Jain, & Calhoun, 2004), encourage multimodal strategies that improve community and social organization, and adopt a comprehensive strategy to promoting the health of boys and young men of color (Heinze et al., 2016). Also similarly, research suggests that not all interventions and case-management strategies have equal effect (Cheng, Wright, Markakis, Copeland-Linder, & Menville, 2008; Aboutanos et al., 2011); this heterogeneity suggests that an analysis similar to Lipsey's examining success of individual program factors rather than the models themselves would be helpful.

Examining a third model for violence prevention gives insight into the complexity of research, evaluation, and program development in this field. Cure Violence (CV) seeks to halt the epidemic/transmissible nature of

violence through Violence Interrupters who actively mediate and de-escalate street conflicts occurring in real time, an innovative intervention which works in tandem with more traditional outreach workers and case management (Butts et al., 2015). In summarizing the evidence of Cure Violence programs, the authors note

broader challenges and limitations to research and program evaluation that are instructive for Wilmington (Butts et al., 2015, pp. 47 - 48):

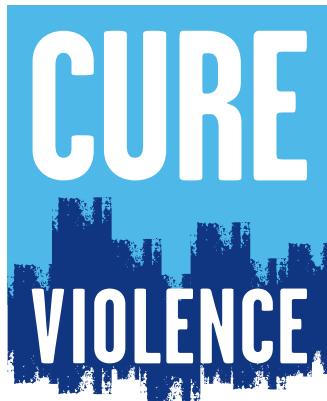
- Controlling for confounding factors is crucial but difficult, especially if reduction in shootings is the outcome measure
- To do this, random assignment on the neighborhood level is needed, but would require "as many as 15 or 20 in each condition, perhaps more" (p. 47)
- Random assignment may be impractical, as it would require several years with rigorous program design to monitor program fidelity and ensure no crossover contamination between intervention and control sites

- "...few cities have enough neighborhoods with sufficient numbers of shootings to reliably measure change over time" (p. 48)

- Clustered random assignment with closely matched pairs is impractical because neighborhoods are often contiguous and interventions may require travel across neighborhood boundaries
- Law enforcement interventions or other community actions may change in response to surges in crime, confounding measurement

Their concluding recommendations for Cure Violence programs have direct application to quasi-experimental designs more broadly:

- Implementation measures should encompass regular recording of all program activities...
- Establishing baseline measures is particularly important because, too often, program evaluations begin after the treatment has been implemented, hampering true measurement of pre-intervention outcomes.
- Neighborhoods selected for evaluation should have an average population size of 10,000 residents and report at least 40 shootings per year.
- The CV model is designed to affect not only the behavior and attitudes of program participants but also the behavior and attitudes of individuals in their social networks. Any sampling design for interviews and surveys may need to distinguish at least three types of research subjects: program participants, other high-risk individuals who are known to and socially networked with program participants, and the broader resident populations of high-risk communities.
- Before evaluation commences, researchers should ensure that the local police department is willing to share crime incident data that capture fatal and nonfatal shootings at the address level.
- Ideally, an evaluation would have access to police shooting data at least 60 months prior to and 30 months after CV implementation. These data would allow for interrupted time series analyses as well as difference-in-differences evaluation methods.



4) Implement interventions

Following an all-time high in 2017 for firearm injuries, 2018 has seen a reduction by approximately 60%; this may be attributed to new public safety strategies emphasizing community policing and a data-driven approach (though details on methods are not public), the latent effect of prior arrests, and perhaps some element of regression to mean (“Finally, Good,” 2018). While exciting and hopeful news, the evidence presented here suggests broader systemic changes must take place to sustain changes.

A summary of the strategic efforts from six CDC funded National Centers of Excellence in Youth Violence Prevention (YVPC) makes several important points on how researchers can work to construct “packages” of effective interventions: help communities to understand the role and requirements of evidence-based practice,



carefully select programs and cultivate capacity (both innovation-specific and general organizational), and coordinate and align efforts within the community (Kingston et al., 2016). For example, in high capacity communities

EVALUATING STRATEGIES TO PREVENT YOUTH VIOLENCE

The Centers for Disease Control and Prevention (CDC) is a leader in youth violence prevention research. CDC:

- Collects data and monitors trends in youth violence;
- Assesses factors that increase risk and factors that protect youth;
- Evaluates programs and strategies aimed at preventing violence; and
- Supports adoption of evidence-based programs and practices in communities through CDC's technical package for prevention.

that already had active intervention programs, packaging meant aligning existing resources and adding complementary programs. For low capacity communities, either no interventions existed or could not be easily scaled, trust did not exist between potential partners, or took significant time (for one example 18 months) to build capacity before program implementation could begin. Consequently, the role of researchers also varied: in one context, they helped align and develop program evaluations for existing efforts; in others, they were more directive in selecting programs, developing needs assessments, forming advisory boards, and providing data.

Wilmington is well on its way to building such capacity. Following the work of the original report, the CDC Advisory Council – a broad coalition of 38

representatives from public, private, government, and non-profit agencies – published a blueprint in 2017 for a comprehensive response to youth adult violence, which calls for a combination of care coordination, interventions, and policy changes (“Community,” 2017). While these improve the capacity of the community to meet a constellation of needs, one of the critical next steps will be designing a blend or “package” of well-planned programs and evaluations to address populations at different levels of risk in ways that are careful not to profile or stigmatize, especially those at the highest risk of injury: youth offenders transitioning back into communities from juvenile detention, violently injured patients presenting to the hospital for their injuries, individuals with gang affiliation or proximity, and other community-identified members in crisis. There is no better opportunity than now for community engaged researchers to leverage their data-oriented skill and knowledge set to advise the service organizations and institutions represented in the CDC Advisory Council (now known as the Wilmington Community Advisory Council) in carefully designing and implementing these programs. Well-designed research not only serves the community by maximizing effectiveness and yielding actionable data locally, but can help propel the state of Delaware as an innovation leader in eliminating one of our most devastating health disparities.

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The DPH Bulletin

From the Delaware Division of Public Health

October 2018



On Sept. 10, 2018 at the New Castle County Public Safety Building, Delaware Governor John Carney signed three bills to fight the addiction epidemic and save lives. One bill creates the nation's first overdose system of care. Photo by Jill Fredel.

Governor John Carney signs legislation creating the nation's first Overdose System of Care

At a Sept. 10 bill signing, Governor John Carney signed three bills to save lives threatened by the addiction epidemic. All are priorities of the state's Behavioral Health Consortium. Senators Stephanie Hansen, Bryan Townsend and Representatives David Bentz and Helene Keeley sponsored the bills.

The new laws will:

- Create the nation's first Overdose System of Care to improve care, and treatment of patients who overdose. According to Department of Health and Social Services officials, the Overdose System of Care will help to better transition individuals after an overdose from an ER setting to more comprehensive treatment.
- Link patient care data related to overdoses collected by DPH's Office of Emergency Medical Services or the state epidemiologist with data in the Prescription Monitoring Program.
- Encourage prescribers and patients to consider using proven non-opioid methods of treating back pain.

Don't forget your flu shot!

DPH advises Delawareans age 6 months and older to get their flu shots by the end of October. Find the DPH flu clinic schedule and flu information at flu.delaware.gov or call 1-800-282-8672.



DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health

Community Partner Support Unit brings social services to the community

Delawareans who qualify for state benefits sometimes need help connecting to assistance programs. The Division of Social Services' (DSS) Community Partner Support Unit (CPSU) serves as a bridge between the Delaware Department of Health and Social Services and service organizations.

CPSU works with nearly 300 community partners to help individuals apply for Temporary Assistance for Needy Families (TANF) benefits, general cash assistance, the Supplemental Nutrition Assistance Program (SNAP), child support, and Medicaid.

CPSU also connects Delawareans to resources for housing, energy assistance, behavioral health, and employment and training.

The CPSU partners with more than a dozen employers to provide case management, subsidized wages, and transportation services to businesses that agree to hire DSS clients.

"The CPSU helps increase access to services by going where our clients are and helping people find and keep jobs that can lead them to self-sufficiency," said DSS Director Ray Fitzgerald.

You'll find the CPSU at libraries, community centers, health fairs, and events. Their offices are in Claymont, Wilmington, Dover, and Milford.

For more information, visit

<https://www.dhss.delaware.gov/dhss/dss/cpsu.html>, call 302-792-0900, view this [video](#), or email community_partnership_support_unit@state.de.us.



Monique Edwards, left, and Dana Cook, center, both of the Division of Social Services' Community Partner Support Unit, shared resources at an event the CPSU organized in August. It was held at the Porter State Service Center in Wilmington. Photo by Brian Aiken/CPSU.

The DPH Bulletin

From the Delaware Division of Public Health

November 2018



Division of Public Health (DPH) Director Dr. Karyl Rattay, far left, visited Delaware Technical Community College's Wilmington campus on Oct. 30 to celebrate Radiation Protection Week with Radiologic Technology students and professors. Also pictured are Frieda Fisher-Tyler (second from left), who leads DPH's Office of Radiation Control; Authority on Radiation Protection Chair Dr. Frances Esposito (third from left); and DTCC President Dr. Mark Brainard, third from right. Photo by Donna Sharp.

DPH and partners celebrate Radiation Protection Week Nov. 4-10, 2018

Division of Public Health Director Dr. Karyl Rattay and the Office of Radiation Control (ORC) traveled to Delaware Technical Community College's (DTCC) Wilmington campus on Oct. 30 to celebrate Radiation Protection Week, which Governor John Carney proclaimed as November 4-10, 2018 in Delaware. DTCC's Radiologic Technology students are educated through a partnership with Christiana Care Health System to achieve national credentials in radiologic technology, nuclear medicine technology, and dental assisting. ORC certifies radiation technologists and technicians, and inspects radiation service sites and equipment.

Visit the Authority on Radiation Protection at www.deradiationprotection.org to learn how radiation protects and enhances personal health.

Diabetes Wellness Expo is Nov. 13

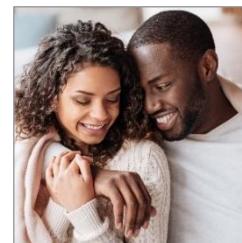
The Delaware Diabetes Coalition is hosting the 2018 Diabetes Wellness Expo on Nov. 13, 2018 from 9:00 a.m. to 3:00 p.m. at the Dover Downs Conference Center, located at 1131 N. DuPont Hwy. in Dover, Delaware. Free admission provides access to diabetes information, exhibitors, giveaways, health screenings, and educational information on diabetes management, nutrition, exercise, and related health issues. For more information, visit www.dediabetescoalition.org or call 302-388-9728.



DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health

Expedited Partner Therapy now legally permitted in Delaware

Expedited Partner Therapy (EPT) is now allowed by law in Delaware, following the signing of Senate Bill 157. EPT is the clinical practice of treating the sexual partners of patients clinically diagnosed with an STD by providing a prescription, or dispensing medications to the patient to take to his/her partner without the health care provider first examining the partner. EPT's purpose is to decrease the rate of reinfection and transmission of STDs to other partners.



EPT is not a mandate. For more information, visit DPH's EPT website: <http://www.dhss.delaware.gov/dhss/dph/dpc/ept.html>.

Prepare now for winter weather

When the leaves fall, review how prepared you are for winter storms, extreme cold, and power outages. The Delaware Emergency Management Agency (DEMA) provides these suggestions:

- Have a household emergency kit containing water and food for household members and pets. Also keep an emergency kit in your vehicle. Visit PrepareDE.org for helpful checklists.
- Keep extra blankets on hand and within reach. Each household member should have a warm coat, gloves or mittens, a hat, and water-resistant boots. Hypothermia, when the body becomes chilled, can be deadly.
- Stay inside during storms.
- Keep gas tanks full in case of emergency and to prevent fuel lines from freezing.
- Avoid unnecessary driving during storms and be aware of traffic restrictions before you drive. Let someone know your destination, your route, and when you expect to arrive.
- A winter storm WARNING means that severe weather such as heavy snow or ice is coming. A BLIZZARD WARNING means to expect strong winds, blinding wind-driven snow, and dangerous wind chill. Seek shelter immediately!



Assessing Delaware Parents' Knowledge, Attitudes and Preferences About Long Acting Reversible Contraceptives for Teens Using Participatory Action Research

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Abstract: To decrease barriers to long-acting reversible contraception (LARC) for teens, this study aimed to reveal knowledge, attitudes, and beliefs that parents have about LARC.

Methods: A participatory action research approach was used. We recruited a diverse group of community researchers who participated in all phases of our study. Four focus groups were recruited using snowball sampling. Two researchers used a values coding process to code data independently. The team met to identify emerging themes.

Results: The 46 parents were predominately female and ethnically diverse. Preventing teen pregnancy was salient

although a double standard between parents of boys and girls became apparent. A key theme that emerged was the importance of prevention of sexually transmitted infections (STIs). There were some reservations about LARC provision in school-based health centers. Another theme was the need for access to confidential birth control for other teens but not for their own teens. Lastly, the advantages of LARC mentioned were effectiveness and ease of use. The disadvantages were increased STIs, risky behavior, hormonal changes, and side effects.

Conclusion: Most of the parents in our study had limited knowledge of LARC. They were aware of its benefits but were uneasy about actual and perceived side effects.

Introduction: Teen pregnancy continues to be a significant public health and socioeconomic issue in the United States and in Delaware.¹ This is despite the significant decreases in teen pregnancy, birth, abortion, and sexual activity rates over the past two decades in our state and country.^{1,2} Delaware has a teen (15-19) pregnancy rate higher than the national average (46 vs 43/1000 girls) and has the 3rd highest pre-teen (10-14) birth rates.² Delaware Latinas ages 15-19 have the highest Hispanic teen pregnancy rate in the country (95/1000 girls) and girls in Delaware have the 5th highest black teen pregnancy rate (76/1000).² The consequences of teen pregnancy affect teen fathers, teen mothers, their offspring, and society as a whole. These include reduced academic and career achievement, infant mortality, behavioral health problems, and increase taxpayer expenditures on public services.³ Delaware teens also have the 4th highest teen abortion rate in the US.²

Despite the marked decrease in teen pregnancy rates, sexually transmitted infection (STI) rates amongst teens and young adults are at record highs.⁴ In 2017, 2.3 million STI cases were reported.⁴ That is 200,000 more cases than 2016.⁴ Delaware's chlamydia and gonorrhea rates are amongst the top 15 in the United States.⁵

with more effective contraceptive methods) is the ideal contraceptive practice for teens.⁹

Nevertheless many places where Delaware teens received reproductive health care (school-based health centers, walk-in teen clinics, detention centers, Job Corps, pediatricians' offices, etc.) did not provide LARC for teens at the start of this study. Practitioners at these sites were concerned about the administration of LARC in teens without parental knowledge or consent, although teens can legally consent to these services in Delaware. Because traditionally these services were provided to older women and by gynecologists it was unclear if the community would be accepting of these new guidelines and of non-gynecologic providers providing this care.

At the same time that we received funding for this project the Delaware Contraceptive Access Now (CAN) started.¹¹ This effort by the state in partnership with the nonprofit Upstream USA is a transformative project to reduce unintended pregnancy. Delaware CAN's goal is to increase access to contraception for all women of reproductive age so they are empowered to become pregnant only if and when they want to.¹¹ The concept inspired by the CHOICE Project which decreased unintended pregnancy by increasing access to any



Nearly a quarter of Delaware 9th graders and nearly two-thirds of Delaware 12th graders have had sex.⁶ Sixty-nine percent of Delaware's sexually active teens did not use any form of hormonal birth control the last time they had sex.⁶ Oral contraceptive pills and condoms are the most commonly used form of contraception for teens.^{6,7} Long acting reversible contraception (LARC) has been shown to be the most effective form of birth control for women of all ages.^{7,8,9} In 2014, the American Academy of Pediatrics recommended that LARC be considered the first line contraceptive choice for adolescents.⁸ There is some concern that teens who use LARC methods will decrease use of condoms and that could lead to increased STI risk in this population.¹⁰ More recently, the American College of Obstetrics and Gynecology emphasized that dual method use (condoms paired

method a women wanted including LARC.^{11,12} While Delaware CAN is not particularly a teen pregnancy prevention intervention, 77% of teen pregnancy is unplanned.^{1,2}

From a public health standpoint, it makes sense to increase access to contraceptive services. However, access is just one of the barriers to community uptake of a public health intervention. Reproductive coercion is defined as threats or behaviors that influence reproductive decision to pressure an individual into initiating, keeping, or terminating a pregnancy.¹³ Historically partners, health care professionals, governments, and courts have coerced women into using contraception with both well-meaning and nefarious intentions.^{9,13,14} Vulnerable communities such

as minorities, low income, disabilities, at risk youth, immigrants, and those involved with the justice system have been targets of reproductive coercion in the past and may be more hesitant to participate in clinical trials or public health efforts due to these prior abuses.^{9,14} Thus our team sought to explore how accepting these communities would be for LARC for their teens.

The specific aims of our project were to reveal current knowledge, attitudes and beliefs that Delaware parents of teens have about LARC, to understand parental preferences about administration of LARC, and to disseminate results to the public to help decrease barriers to LARC for teens.

Methods: In order to address potential community concerns around LARC use in teens, a participatory action research approach was chosen. Participatory Action Research (PAR) is a research approach that emphasizes participation of community members with a focus on actionable data.¹⁵ This project was led by an academic principal investigator (PI) and community co-investigator (CI). We recruited a diverse group of community researchers who were parents of teens and they participated in all phases of our project (study design, data collection, data analysis, and dissemination).



Contraceptive implant

Focus group participants were recruited using snowball sampling via social networks, affinity resource groups of a hospital, and a workforce development program. In order to be sensitive to racial/ethnic concerns and differences regarding contraception, we chose to cluster focus group participants by their race/ethnicity. We held four two hour long focus groups (2 White, 1 Black, 1 Latina) led by 1-2 community researchers who matched the ethnicity of participants. Group discussions were led by community researchers and the PI using a 36-question semi-structured discussion guide that was developed by the entire research team using the integrative behavioral model. Participants were compensated for their time and opinions by receiving dinner and a \$55 gift card.

Two researchers used a values coding process to code data independently (manually and with NVivo 8). The researchers then met with the research team to identify emerging themes and resolved discrepancies by consensus.

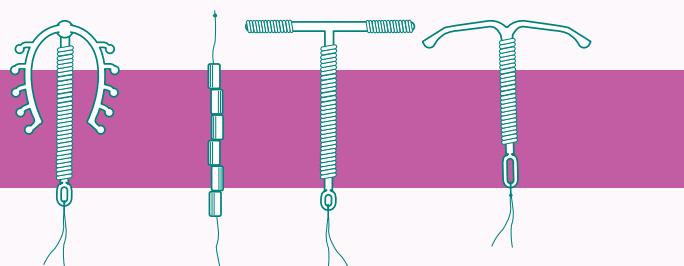
Results: The 46 focus group participants were predominately mothers of youth ages 9-20 and ethnically diverse. The majority thought their teens were (24%) or possibly (28%) sexually active. seventeen percent of the parents in our focus groups have used a LARC method (See Table 1). There were a few themes that emerged as the result of our focus group discussions.

Importance of Teen Pregnancy Prevention:

Girls>Boys

Preventing teen pregnancy was salient although a double standard between parents of boys and girls became apparent.

I have a son and a daughter. My views and concerns are very different because I have to worry about the possibility of her getting pregnant but with him, I have to show up at somebody else and say, "Oh! Sorry about that." (Latina Participant)



Intrauterine device (IUD)

I don't think it should, but I think it does. I think unfortunately generally what happens when a teenage girl becomes pregnant, then that responsibility falls on her family. It's unfortunate but that is what happens. I do think it becomes more important for their family to make sure their daughter does not become pregnant. Where the parents of the boy are like, "Boys will be boys" and see what happens. (White participant)

Unfamiliarity with LARC methods for teens

Parents could list all methods of birth control including LARC but were not familiar with LARC methods. The advantages of LARC mentioned were effectiveness and ease of use. The disadvantages were increased STI risk, hormonal/body changes, and worries about infertility. (See Figure 1)

You got just everything now so I'm not privy to all these birth controls. I tried Depo, I blew up, but I'm like, if it ain't natural and what should be stopping your cycle when that's a God-given thing and that should come naturally. They got pills, they got stuff to go on the arm, then you can see it and I don't know enough about it that I would want my child to try this. (Black Participant).

Preventing sexually transmitted disease is as important as pregnancy prevention

Despite there being only one question in the focus group discussion guide about LARC and STIs, the importance of STIs was a key theme that emerged in all the focus groups. Parents were concerned both about risky behavior and decreased condom use in teens who used LARC methods. They also wanted to make sure STI prevention was being discussed by LARC providers. Condoms were thought of a method that had no side effects and had the benefit of protecting against pregnancy and STIs.

Condom I think is a better thing, because avoid pregnancy, avoid transmission of disease (Latina participant).

Sometimes I feel a great threat of diseases as a consequence rather than pregnancy should my teenager become sexually active (White participant).

Confidential Services are for those kids not my kids

Another theme was the need for access to confidential birth control services for teens of other parents but not necessarily for the teens of the focus group participants.

I'm okay with this, only because I think there's a lot of children don't have the parental support that we have in this room, and there's a lot of teen pregnancies in homes where they don't have the traditional structure, or parents are working all the time, so I would rather they have access than not. (White participant)

So of course, you wouldn't want your child going in because you feel like you have a relationship but for those parents that don't or they aren't comfortable. Like for me, when I was growing up I had something like that, that I felt comfortable because my mom didn't talk to me. That's why I'm not against the idea of it because I think who that service is there to serve. (Black participant)

Reservations about LARC at SBHCs

While accepting of the provision of birth control in SBHCs, parents were concerned about LARC services in SBHCs due to concerns about lack of a sterile environment and lack of additional personnel available that would be available in a doctor's office or hospital. In addition there were concerns that there may not be as much privacy in a SBHC compared with a traditional health care provider setting. Lastly, there were concerns about younger teens accessing these services in a SBHC.

*It's {school clinic} not a sterile environment.
(White participant)*

*The kids in school, everybody know everybody's business.
(Black participant)*

Population Control

Although not a central theme, the two minority groups did discuss the use of LARC to control or limit their ethnic population. In the black group there was more of a concern that violence would limit the growth of their population than the increased use of LARC. Neither of the two white groups thought this was a concern.

*I do want to make a statement. I've got nothing against you that you are facilitating this session. So I'm always suspicious at nature, so these questions that if {local health care system} is sponsoring it gives me the impression, that {local health care system} is trying to target the Hispanic community for LARC. Then what's the underlying agenda there? Is it that we're overpopulating and there are too many kids coming out of our community, so let's stop the population, so let's give them LARC? Seriously I get very suspicious at first. I have read a lot of stories. (Latina participant)**

If more Black men's keep getting killed, it's going to slow it {the population} down. (Black Participant)

*Name of local health system edited out to maintain confidentiality.

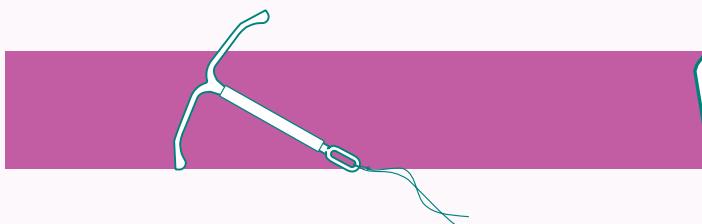


Discussion: Prior studies have focused on patients and providers' contraceptive beliefs, usage/provision rates, and/or accessibility to contraception. A few have surveyed parents or the public's beliefs about confidential care and access to contraception. Furthermore none have taken an in depth approach to the use of LARC specifically. This is important as LARC differs from other forms of contraception in that it requires invasive procedures that lead to implantable birth control methods that cannot be stopped without provider intervention.

This qualitative study of Delaware parents knowledge, attitudes, and preference about LARC use in teens is our group's first step to understanding what themes are salient to parents. Most of the parents in our study had limited knowledge of LARC. They were aware of its benefits but were uneasy about actual and perceived side effects. They were receptive to birth control for teens in all health care settings but had some concerns with LARC being provided in SBHCs. Many participants expressed a desire for communication and involvement with their teen's birth control decisions but understood the need for confidential services especially if those services were for other people's kids. Most importantly they want to be reassured that LARC providers will continue to emphasize STI prevention.

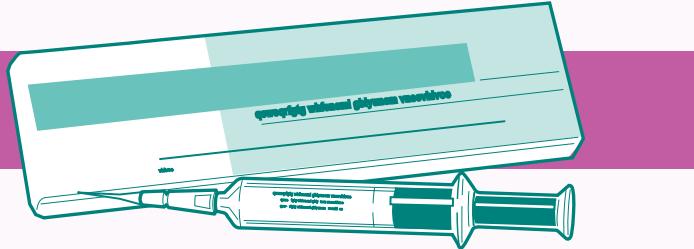
perceive a cause and effect relationship that could lead to decreased uptake of these highly effective methods of contraception.

There were a few limitations to this study some of which are inherent to a qualitative study design. This was a small study of mostly highly educated, biological mothers of teens in New Castle, County and the results may not be generalized to other parents/guardians in the rest of the state or outside of the state. We used the themes that emerged in this study to create a quantitative survey which was distributed to a larger sample statewide. New Castle County, Delaware is a small part of a small state so participants may know each other and the subject matter was very personal. Focus group participants may have not wanted to share their true feelings on this subject due to concerns for confidentiality and due to social acceptance bias. The PI and CI were both providers of adolescent reproductive health services in the area and attended and/or co-facilitated each group which could have led to moderator acceptance bias. We tried to control for this by having the community researchers be the lead group facilitators and by having other research team members present and taking notes during the group in order to decrease bias. We also tried to decrease analysis bias by validating emergent themes with the multiple members of the research team.



Intrauterine system (IUS)

LARC use in women of reproductive age is a hot topic in our state and around the country. There are many studies that look at adult and adolescent patient acceptance of LARCs but not many that look at how the community views these services. Parents are still the primary influencers of their teens and their opinions about this form of birth control can be a barrier or a facilitator to their teen's access to services. Our study shows that parents are open to these methods but may have some reservations. STI rates are increasing locally and nationally amongst youth and young adults during the same time that LARC use is increasing in this population. While there are no studies that explicitly link the two phenomena, communities may



Contraceptive injection

Conclusions: Preventing teen pregnancy is still very important to parents of teens although it was more important for their daughters than for their sons. Parents had some but not always accurate or extensive knowledge about LARC methods. They had concerns about safety of LARC methods and that teen LARC use would lead to riskier behavior and increased STIs. Parents want communication and involvement with their own teen's contraceptive choices but were accepting of confidential services for kids of other parents.

Recommendations:

1. Craft teen and parent of teen-specific messaging regarding LARC that addresses safety, future fertility,

STI prevention, and why condoms alone is not sufficient to prevent pregnancy.

2. Ensure through evidence-based research that STI rates are not increasing due to increased use of LARC amongst teens (ex: tracking contraceptive method on STD reports, LARC registries, etc.)
3. Target boys and parents of boys as important parts of teen pregnancy prevention and LARC education efforts.
4. Be sensitive to concerns of reproductive coercion of vulnerable populations and make sure practice policies and procedures are vigilant to avoid real or perceived coercion.

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Table 1. LARC PAR Focus Group Demographics.

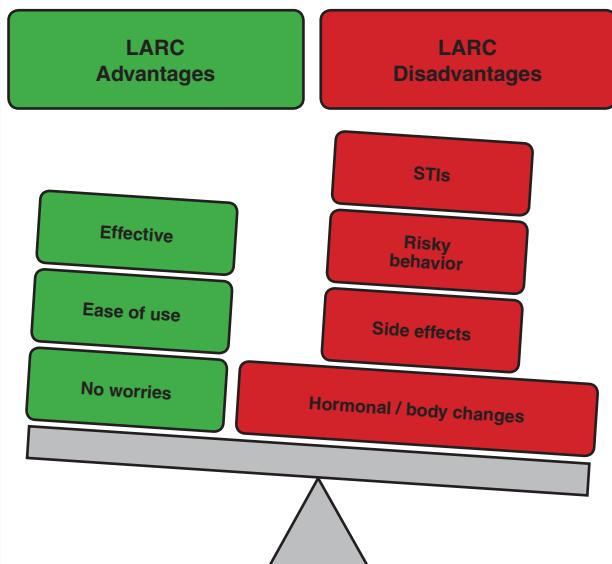
Gender	90% Female	10% Male		
Parenting status	95% mother of father of teen	1 Grandparent	1 stepparent	
Education	27% Advanced Degree	22% College	20% High School and some College	
Race/Ethnicity	50% White	30% African American	20% Hispanic	
Religion	74% Christian	24% No preference		
Residence	70% Suburban	26% City	100% New Castle County, DE	
Income	33% >\$100,000	20% \$50-99,000	26% \$25-49,000	17% <\$25,000
Insurance	78% Private	22% Medicaid		
Works In Healthcare	72% No	18% Yes		
Sexually Active Teen	24% Yes	28% Unsure		
Use of LARC	17%	7 IUDs	1 implant	

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- 7.) <https://www.guttmacher.org/fact-sheet/contraceptive-use-united-states>
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- 10.) <https://jamanetwork.com/journals/jamapediatrics/fullarticle/2502624>
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- 12.) <https://contraceptivechoice.wustl.edu/what-we-do/pathway-to-choice/>
- 13.) <https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/Reproductive-and-Sexual-Coercion>
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- 15.) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2566051/>

Figure Legends:

Figure 1. LARC Advantages and Disadvantages.





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Addressing the Sexual Health of Delaware Teens through Evidence-Based and Promising Education

*Christopher C. Moore, B.A., LSSGB
Nicole A. Fournakis, B.S.*

Objective

Readers will be able to identify the impact of the Alliance for Adolescent Pregnancy Prevention (AAPP) in improving knowledge and attitudes regarding risky sexual health behaviors.

Methods

Three AAPP, Be Proud! Be Responsible!(BPBR), Making Proud Choices! (MPC) and Wise Guys: Male Responsibility (Wise Guys), are assessed using 3 similar pre- and post-surveys which are designed specifically for these curricula. These surveys measure changes in knowledge and attitudes toward sexual health and risky behaviors at baseline and completion of the course.

Results

In Delaware, adolescents who completed any of the three AAPP programs have shown an increase in knowledge

around condom usage; an increase in awareness of the factors around safe sexual health practices and healthy relationships; and, a positive change in attitude around communication – both with a partner and their parent(s)/guardian(s). Post-survey scores improved for BPBR, MPC and Wise Guys by 8%, 18% and 8%, respectively.

Conclusions

Reproductive health education is essential for teenagers, giving them the tools to make safer choices if they choose to have sex (Delaware Department of Health and Social Services, n.d.). In Delaware, the Youth Risk Behavior Survey (YRBS) indicates that teens continue to take risks with their sexual health. Programs like AAPP have the capacity to continue to make a positive impact on reducing the risk of STI and HIV transmission, along with potentially lowering the number of teens who become pregnant.

Introduction

Teens and young adults in the United States represent 25 percent of the population who identify as sexually active; however, these adolescents make up 50 percent of the new cases of sexually-transmitted infections (STI)



each year (CDC, 2017). In 2016, the state of Delaware climbed the rankings to number eight in the nation for the incidences of Gonorrhea and Chlamydia, especially in teens (Centers for Disease Control and Prevention, 2016). Annually, rates of STIs continue to rise across Delaware (Newman, 2017). In addition, unintended pregnancies and teen birth rates have declined nationally by 63% within the last 25 years; however, Delaware still ranks high compared to national levels (Trends in Teen Parenting, 2016). Delaware teens consistently reported high rates of sexual activity in the 2017 Youth Risk Behavior Survey (YRBS). Delaware ranks high among all states in sexual activity, number of sexual partners, and age at which students begin to have sex. As of 2017, Delaware's rates of sexually active teens, and teens who became sexually active young, ranked 2nd highest in the nation of states who participated in the survey (Delaware Department of Health and Social Services, n.d.). These high rates of STI or pregnancy incidence in teens are not a coincidence; conversely, they are the result of risky behaviors that are characteristic of teens. While there has been a call for state and local health departments to initiate efforts around rapid detection and clinical treatment, an argument for focusing on education and prevention to mitigate these risky behaviors can be made. Research shows that education around risk-reduction strategies and contraception can help youth delay sex, use condoms or contraception, and be monogamous (Alford S, et al, 2008). Moreover, another study found that teens who received comprehensive sex education were 50% less likely to get pregnant and conversely, risk of HIV and STIs significantly drop as a result of these education programs (Kohler et al, 2008). Given the high STI ranking and unintended teen pregnancies and births in Delaware, there is a

prime opportunity to use education to reduce these risky behaviors from teens through a comprehensive, evidence-based teen education program. The Alliance for Adolescent Pregnancy Prevention (AAPP) is doing just that: it provides quality reproductive health education across the state, and efforts to implement more rigorous evidence-based interventions are proving successful. With this high-caliber program in place, Delaware will become a national model for collective impact in public health, most especially for this youth population. These AAPP programs often serve as a compliment to larger programs and services available to teens, including the School-Based Health Centers, community centers and faith-based initiatives.

Methods

The Alliance for Adolescent Pregnancy Prevention (AAPP) is a partnership between Christiana Care Health System and the Delaware Division of Public Health, providing Delaware youth with skills and information

A screenshot of the Christiana Care Health System website. At the top, there is a navigation bar with links for "Our Services", "Patient & Visitor Guide", "Health & Wellness", "About Us", and "For Health Professionals". Below the navigation bar, the Christiana Care logo is displayed next to the text "CHRISTIANA CARE HEALTH SYSTEM". To the right of the logo are links for "Careers", "Find a Doctor", "Pay My Bill", "Volunteer", "Press Room", "Contact", and "Make a Gift". There is also a search bar with a magnifying glass icon. The main content area features a photo of a smiling young couple. To the right of the photo, the text "Center for Community Health" is visible. On the left side of the content area, there is a sidebar with links for "Center for Community Health", "About Us", "Adolescent Pregnancy Prevention", "Camp FRESH", "Health Ambassadors", "Our Staff", and "School-Based Health Centers". On the right side, there is a section titled "Alliance for Adolescent Pregnancy Prevention" with descriptive text and links for "Related Pages", "About Us", "Center for Reproductive Health", "Wilmington Health Center", and "Women's Health". Below this section, there is a link "For more information about AAPP, call 302-320-6525." At the bottom of the content area, there is a link "Center for Community Health" with the address "1400 N. Washington St., 4th Floor, Wilmington, DE 19801" and a phone number "302-320-6793".

to help avoid or reduce involvement in risk behaviors, particularly high-risk sexual behaviors, and to promote positive youth development. More specifically, AAPP works to reduce the number of teenagers who are sexually-active, become pregnant and become teen parents. AAPP offers evidence-based and promising programming statewide for young people. It also serves physicians, educators, nonprofit groups and anyone else who provides care for teens and their families. Currently, AAPP provides three programs: two evidence-based curricula, Be Proud! Be Responsible! (BPBR) and Making Proud Choices! (MPC); and, Wise Guys: Male Responsibility (Wise Guys), which is designated a promising program by the Centers for Disease Control.

The two evidence-based curricula – BPBR and MPC – are designed to empower young adolescents (13-18 year-olds and 11-13 year-olds, respectively) to change their behavior in ways that will reduce the risk of becoming infected with HIV and other STIs, and their risk of becoming pregnant. These programs emphasize the reality that teens, especially those who are at-risk, have the power can reduce their own risk for STIs, HIV, and pregnancy by using a condom when choosing to have intercourse (Canfield-Davis, Jain & Meyer, 2011). As abstinence-plus curricula, BPBR/MPC also discusses the importance of understanding that abstaining from sexual behaviors is the most guaranteed risk-avoidance behavior. With social media and access to sexually-explicit media are influencing young people, now, more than ever, not all teens will choose abstinence. (Landry, et al, 2017). Both BPBR/MPC are designed to address specific objectives related to knowledge, attitudes, and behaviors around sexual health. At the completion of the BPBR/MPC curricula, youth are expected to have (1) increased knowledge about prevention of HIV, STDs and pregnancy; (2) increased positive attitudes/beliefs about condom-use; (3) increased confidence in their ability to negotiate safer sex and to use condoms correctly; (4) stronger intentions to use condoms if they have sex; and, ultimately (5) a lower incidence of STD/HIV risk-associated sexual behavior and (6) stronger sense of pride and responsibility (Jemmott, Jemmott & McCaffree, 2015). The former is delivered over 6, 1-hour sessions, the latter over 8, 1-hour sessions, thus giving BPBR participants 60 and MPC participants 80 hours of education.

In addition, AAPP also provides a program targeting males: Wise Guys. This promising program is designed to prevent adolescent pregnancy by reaching adolescent males, which makes it unique from the majority of curricula. The program acknowledges young males as "whole" individuals with a variety of needs and desires (Children's Home Society of North Carolina, 2017). Interactive lessons and activities focus on assisting participants to question their own identity, their future goals and what steps they would need to take to turn goals into successes. The curriculum focuses on understanding one's self, values, future goals, and sexuality. In addition, Wise Guys addresses personal and family values, communication and theories around "masculinity", dating violence, abstinence and contraception, STI and HIV-prevention and the impact of teen parenting.

All three AAPP programs are assessed using pre- and

post-surveys which are designed specifically for each curriculum. The surveys for BPBR and MPC are required to be used as all aspects of these curricula must be delivered with fidelity, including the assessment (Jemmott, Jemmott & McCaffree, 2015). The Wise Guys survey, while not validated, was created by the authors, Children's Home Society of North Carolina, and is the preferred assessment tool to be used by agencies delivering the program.

These surveys measure changes in knowledge and attitudes toward sexual health and risky behaviors. The Wise Guys surveys also measures efficacy around condom use and perception of ability to communicate with parents.

Results

Between July 2016 and June 2017, AAPP reached 609 teens through education across the state of Delaware. Of this number, 53% were male and 47% were female. The average age for an AAPP participant was 15, and the majority of the participants across the 3 programs self-identified as a racial minority (African-American, Hispanic/Latino, and multi-racial). Of the total number of teens who signed-up for an AAPP group, 84% completed the program. The three programs were implemented in middle and high schools, public, private and charter, and in community sites ranging from Boys and Girls clubs to a summer camp. Teens that completed these programs have shown an increase in knowledge around condom usage; an increase in awareness of the factors around safe sexual health practices and healthy relationships; and, with Wise Guys specifically, a positive change in attitude around communication – both with a partner and their parent(s)/guardian.

Be Proud! Be Responsible!

The data gathered for the analysis of the BPBR program was derived from self-reported pre- and post-test knowledge, attitude, and behavior measures between July 2016 and June 2017. Averaged scores have been used to analyze the change in pre- and post-test results for youth participating in the 6-module program. This assessment was delivered at the first and last session for each group and is comprised of 22 multiple choice questions. Of that number, 17 questions measure knowledge and 5 address behaviors based on knowledge. For the 17 knowledge-based questions, the scores for correct responses increased from 68% to 82% (14%) from pre- to post-test. This included questions related to modes of HIV-transmission and proper

condom usage. For the 5 questions assessing behaviors based on knowledge, the scores for correct responses increased from 63% to 83% (20%) from pre- to post-test. This included questions related to safe sexual practices using condoms. Overall, the number of correct responses increased from 66% to 82% (16%) from pre- to post-test (n=194).

Making Proud Choices!

The data gathered for the analysis of the MPC program was derived from self-reported pre- and post-test knowledge, attitude, and behavior measures between July 2016 and June 2017. Averaged scores have been used to analyze the change in pre- and post-test results for youth participating in the 8-module program. This assessment was delivered at the first and last session for each group and is comprised of 24 multiple choice questions. Of that number, 19 questions measure knowledge and 5 address behaviors based on knowledge. For the 19 knowledge-based questions, the scores for correct responses increased from 62% to 91% (29%) from pre- to post-test. This included questions related to modes of HIV-transmission and proper condom usage. For the 5 questions assessing behaviors based on knowledge, the scores for correct responses increased from 53% to 92% (39%) from pre- to post-test. This included questions related to safe sexual practices using condoms. Overall, the number of correct responses increased from 55% to 87% (32%) from pre- to post-test (n=220).

Wise Guys

The data gathered for the analysis of the Wise Guys: Male Responsibility was derived from self-reported pre- and post-test measuring knowledge, behaviors and attitude, between July 2016 and June 2017.

Average gain scores (converted to percentages) have been used to analyze the significance of different reported gains in pre- and post-test results for youth participating in the 10-week program. The Wise Guys: Male Responsibility pre- and post-test delivered at the first and last session of each group is comprised of 27 questions, ranging from multiple choice, to a measurement of attitudes using a Likert Scale. Of that number, 10 questions measure attitudes, 9 questions measure knowledge, 3 questions assess behavior and 2 questions assess efficacy of condom use. For the 10 questions measuring participant attitudes toward safe

sexual practices, the percentage of positive answers illustrating healthier choices increased from 66% to 85% (19%) from pre- to post-test. For the 3 questions measuring participant behaviors around safe sexual practices, the percentage of positive answers illustrating healthier choices increased from 70% to 86% (16%). For the 9 knowledge-based questions, the percentage correct responses increased from 60% to 93% (33%) from pre- to post-test (n=195).

Discussion

The results from the 2016-2017 school year for these three programs are positive. However, the increases with MPC and Wise Guys participants are more significant. There are some factors which may be impacting this. First, MPC participants receive 2 additional hours of educator than participants in BPBR. In addition, by virtue of being 11-13, MPC participants may not have received any sexual health education in school, prior to this intervention; BPBR participants are more likely to have had at least one semester of sexual health education if they are attending a public high school. Wise Guys participants receive 10 hours of education, and the material focuses on health from a more holistic lens, giving males the opportunity to speak freely about topics they may not otherwise be discussing in other social settings (ex: values, goal-setting and healthy relationships).

It is also worth noting the intent behind the use of 3 different tools to compare 3 different curricula. While the 3 curricula, BPBR, MPC, and Wise Guys, aim to accomplish a positive impact on teen's attitudes, behaviors, and health, each must be unique in delivery to cater to the dynamic teen populations. While both BPBR and MPC are similar in content, their assessment tools and delivery of the curriculum must be tailored to suit the age and attrition level of the participating teens. Even a few years difference between age groups matters in how well a teen can retain curriculum information. Thus, it is critical to measure knowledge and attitudes between the two groups differently to appropriately match by age levels. Wise Guys, while more specific than BPBR/MPC, is unique compared to other adolescent programs nationwide because of its specificity to focus on teen boys. Few programs exclusively consider the health of adolescent boys making Wise Guys a unique addition to AAPP programming. Given the nature of yet another teen population, Wise Guys too needed a separate tool from BPBR/MPC to align the specific curriculum deliverables to adolescent males. It is necessary to compare all curricula together in order

to view all successes and opportunities of the AAPP program for the adolescent population in its entirety. But even adolescents comprise of dynamic characteristics with regard to age (specifically maturity level), gender, attitudes, and beliefs. A single tool of “one size fits all” to measure these dynamic groups would not be feasible or do justice to realistically measure the sought-after outcomes of the AAPP program.

As AAPP staff plan for the future, it is critical to remain aware of the needs of teens that may not comfortably access these programs. This includes Lesbian, Gay, Bisexual, Trans and Queer youth (LGBTQ+), youth of color and youth with disabilities. It is important to acknowledge that curricula used by AAPP, while inclusive frames the education around a heterosexual, non-disabled lens. While the evidence-based curricula comes with the expectation that each is delivered with fidelity, it is critical to also be creative in meeting the specific needs of these populations. While AAPP continues to provide quality, evidence-based and promising education for Delaware teens, there are a number of opportunities which have become a priority as the program plans for the future. This includes strengthening capacity to consistently serve the diverse needs of teens across the state of Delaware, while maintaining fidelity; and, reaching marginalized groups with reproductive health education they may not otherwise be receiving.

Conclusions

AAPPs evidence-based curricula has the capacity to continue making a positive impact on reducing the risk of STI and HIV transmission, along with potentially lowering the number of teens who become pregnant. As such, these reproductive health programs make Delaware the perfect canvas to serve as a national model for collective impact by positively influencing teen health. Adaptations to the curricula will be needed in an ongoing basis for different groups and changing social norms.

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Nicole A. Fournakis, B.S., is a Program Coordinator in Christiana Care Health System's Office of Health Equity. Ms. Fournakis is responsible for oversight of the system's Health Guide Program and is key collaborative lead on a number of evaluation efforts focused on community-based programs, including the Alliance for Adolescent Pregnancy Prevention, Produce Rx and the new School-Based Health Center serving Warner Elementary in Wilmington. She is also co-lead of a pilot to create a curriculum to standardize Community Health Worker training. A native of Colorado, Ms. Fournakis received her Bachelor of Science degree in Neuroscience from the University of Delaware and is currently pursuing an M.P.H. at the University of Massachusetts.



Christopher C. Moore, B.A., LSSGB, is a Senior Manager in Christiana Care Health System's Office of Health Equity. Mr. Moore has oversight of staff, programming and evaluation for a number of the system's community-based initiatives which aim to improve public health across the lifespan. These programs include the Alliance for Adolescent Pregnancy Prevention, one of Delaware's largest providers of evidence-based reproductive health education; Camp FRESH, a nationally recognized program for urban youth; and Christiana Care's Health Ambassador Program, which provides access to education and resources for new and expectant mothers. In addition, he is the co-lead for a Christiana Care Value Institute-funded evaluation focused on the impact of a community advisory board on New Castle County's School-Based Health Centers. Mr. Moore is a proud member of Delaware's sexual health education and research community, providing expertise, lectures and educational opportunities on topics ranging from access to reproductive health services, to understanding the impact of sexually explicit media. In addition, he presents his work at local, national and international conferences focused on public health and has been published in multiple peer-reviewed journals and print publications. In 2016, Mr. Moore joined Delaware Technical and Community College as adjunct faculty in the Department of English.

November 2018

The Nation's Health headlines

Online-only news from The Nation's Health newspaper

Welcome to your digital access to the November - December issue of The Nation's Health. Stories of note include:

- **Navigators continue working to get people insured, despite cuts: Attacks on ACA spur enrollment concerns**

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- **Q&A with NCEZID's Khabbaz: Health threat of antibiotic resistance urgent: New challenge calls on world to take action**

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- **APHA Annual Meeting to rally around 'Health Equity Now': 12,000 expected to gather in San Diego**

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FOGARTY INTERNATIONAL CENTER • NATIONAL INSTITUTES OF HEALTH • DEPARTMENT OF HEALTH AND HUMAN SERVICES

Africa's health, research workforce gets \$26M boost

To further strengthen the health care and research workforce in sub-Saharan Africa (SSA), Fogarty is planning to award about \$22 million over five years, through a new program funded by the President's Emergency Plan for AIDS Relief (PEPFAR). The seven projects being supported by the Health Professional Education Partnership Initiative (HEPI) are intended to leverage the achievements and lessons learned from the previous Medical and Nursing Education Partnership Initiatives (MEPI and NEPI).

A related award will provide nearly \$4 million over five years to fund the African Forum for Research and Education in Health (AFREhealth) which will serve as a leadership and convening organization to network institutions to develop and share innovations, curricula and policy.

...continued on next page

Photo by Richard Lederer/Fogarty



A new program administered by Fogarty will provide \$22 million to improve health care workforce capacity in sub-Saharan Africa.

NIH trying to change science culture, boost women's role

The NIH is strengthening its efforts to end sexual harassment both at the agency and within the research institutions it funds. "Our goal is to create a paradigm shift in the scientific culture wherever NIH research activities take place to eliminate sexual harassment and enhance women's contributions to scientific advancements," NIH Director Dr. Francis S. Collins said in a statement.

Sexual harassment is about power, he said. "It's morally indefensible, it's unacceptable and it presents a major obstacle that is keeping women from achieving their rightful place in science."

In addition to implementing changes inside NIH, the

agency is also bolstering grant oversight procedures to address sexual harassment at NIH-funded institutions. A new website has been developed with information regarding NIH policies, terms and conditions that require NIH grantee institutions provide a harassment free-environment, relevant laws and regulations, and contacts for reporting any incidents. The URL is www.nih.gov/anti-sexual-harassment.

A recent National Academies report found no evidence that current policies and procedures have significantly reduced sexual harassment in academic sciences, engineering and medicine, Collins noted. "It is clear we must do more to change the fundamental culture of our organizations."

Urgent need for dementia research in LMICs

- India study sets stage for U.S. test of screening tool
- Brazilian brains focus of genomics research
- Potential dementia risk factors merit study in Africa

Read more on pages 43 – 46

FOCUS



Africa's health, research workforce gets \$26M boost

...continued from previous page

"Through this new program called HEPI, we are empowering African institutions to tackle the region's most pressing health problems, improve the effectiveness and efficiency of the U.S. response to HIV/AIDS, and reduce the suffering and death the epidemic continues to cause across the region," said Fogarty Director Dr. Roger I. Glass.



The Health Education Partnership Initiative (HEPI) will strengthen innovative training approaches, including e-learning curricula.

The overarching goal of the initiative is to encourage activities that prepare an African workforce capable of meeting the biomedical, behavioral and clinical research needs in PEPFAR-priority countries with a high burden of HIV/AIDS. Grantee institutions are being supported to expand and enhance innovative education models, evaluate and disseminate best educational practices, introduce and test novel training approaches including interprofessional education activities, and enhance opportunities for students to conduct locally relevant research as an integral part of their professional training. In addition, HEPI participants will develop strategies to recruit and

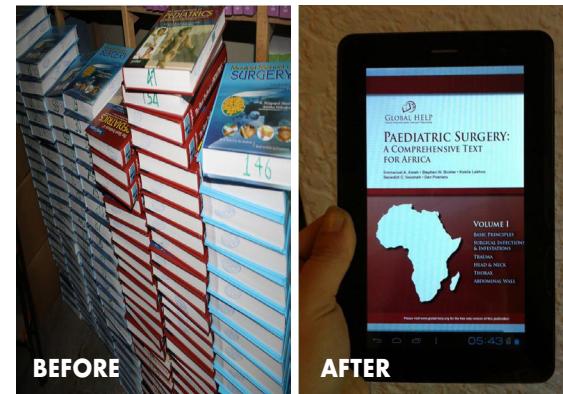
retain qualified faculty, combat brain drain of trainees, increase the number of health professionals in neglected rural areas, and build the human and organizational resources to support research at the institutions. Finally, grantees will consult with stakeholders such as the Ministries of Health and Education to ensure national workforce needs

are being met, and form partnerships to strengthen national networks of African health education and research institutions.

The companion Association award will provide leadership for institutions across Africa, and act as a hub to support joint educational activities with a focus on outreach to broad communities and multiple stakeholders.

These may involve holding an annual symposium, establishing topical working groups, conducting mentoring activities and developing curricula.

HEPI will build on the framework developed through the prior MEPI/NEPI programs. Some key accomplishments included forming a network of more than 60 African medical schools, establishing dedicated offices for grant writing and management, upgrading rural training sites, promoting interdisciplinary education and incorporating research into academic training. In addition, new electronic educational practices were developed, broadband access was enhanced across campuses, e-learning materials were developed and shared, skills labs were established to provide



HEPI will build on progress made under the previous MEPI program, which helped Africa's medical schools move from hard copy textbooks to tablets.

training in procedures, and tablets were provided so students could access current health information. Also, a Principal Investigator council was formed to manage and coordinate activities among participants.

HEPI is administered by Fogarty and funded by PEPFAR, the U.S. response to the global HIV/AIDS epidemic. Begun 15 years ago, PEPFAR now has activities in 50 countries and supports over 14 million men, women and children on HIV treatment.

HEPI awards:

Ethiopia: Addis Ababa University

Kenya: University of Nairobi

Mozambique: Eduardo Mondlane University/Mozambique Institute for Health Education and Research

Tanzania: Muhimbili University of Health and Allied Sciences

Uganda: Mbarara University of Science and Technology

Uganda: Makerere University

Zimbabwe: University of Zimbabwe

AFREhealth award:

Uganda: Makerere University

RESOURCES

<http://bit.ly/AfricanHealthEd>

Research revolutionizes hydrocephalus care

By Karin Zeitvogel

A treatment pioneered and proven with Fogarty support has revolutionized care for hydrocephalus and saved money—and probably lives—in resource-poor and wealthy countries alike. Developed by Dr. Benjamin Warf after he noticed “an enormous number of babies with hydrocephalus” presenting at a Ugandan children’s neurosurgery clinic, the treatment allows doctors to avoid placing a shunt in babies to drain excess cerebrospinal fluid from the brain.

“This is important because half of shunts fail within two years of placement and all fail within five to 10 years,” said Warf. “When they fail, the child has to have emergency surgery or they’ll die from elevated intracranial pressure. But in sub-Saharan Africa and other limited-resource regions, many patients don’t have access to emergency medical systems where they can get immediate care.”

Warf himself placed shunts, the predominant treatment worldwide for hydrocephalus for several decades, in hundreds of babies with hydrocephalus during his first few years in Uganda, but in the back of his mind was the nagging thought that, while he was treating one problem, he was creating another—shunt dependence. So he set about developing a novel treatment for hydrocephalus, combining two methods that had been used individually before, with limited success. One, endoscopic third ventriculostomy (ETV), involves making an opening in one of the ventricles, or cavities, of the brain to allow fluid to drain, and the other, choroid plexus cauterization (CPC), reduces the amount of cerebrospinal fluid the brain produces.

Scientists knew that ETV-CPC is less likely to fail over the long term but didn’t reduce the size of the ventricle as much as shunt placement did, raising concerns that cognitive development would be compromised in children who had the new procedure. So, with a grant through Fogarty’s brain disorders program, largely funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), Warf and his colleagues ran a randomized controlled trial to compare outcomes after ETV-CPC and shunting in babies with post-infectious hydrocephalus.



A health care worker holds a baby with hydrocephalus at the CURE pediatric neurosurgery hospital in Uganda.

Twelve months after surgery, they assessed the neurological development of 100 infants enrolled in the study conducted at the CURE pediatric neurosurgery hospital in Mbale, Uganda. Their findings, published in the *New England Journal of Medicine*, showed that children in the shunt group had smaller ventricles a year post-operation than the ETV-CPC group, but brain growth and developmental outcomes for the two groups were the same. For the first time, research was showing that developmental outcome correlated with brain volume, not

ventricle size. “For the past 50 years, hydrocephalus treatment has been directed at making the ventricle smaller, but we found that what’s important is not ventricle size but whether the brain is growing or not,” said Warf.

The children will be followed for five years after surgery to allow Warf and his colleagues to continue to monitor and assess their development and brain growth.

Warf received a MacArthur Genius award in 2012 for developing ETV-CPC and advancing standards of, and access to, health care in both the developed and poorest regions of the world.

“ETV-CPC is an example of how helping people elsewhere also allows us to make gains for Americans,” he said. U.S. pediatric neurosurgeons have trained in the new technique in Uganda, where the large patient population allows them to perform multiple hydrocephalus operations a day. ETV-CPC has been taken up at major pediatric neurosurgery centers in North America, including Boston Children’s Hospital, where Warf has worked since he left Uganda in 2009. The number of shunts placed by pediatric neurosurgeons at Boston Children’s has been reduced by around a third, meaning fewer revisions when a shunt fails.

Estimates put the total cost in the U.S. of maintaining shunt function at between \$1 billion and \$2 billion a year, so placing fewer shunts is expected to lead to “big cost-savings and a decrease in morbidity and mortality from lifetime shunt dependence,” said Warf.

RESOURCES

<http://bit.ly/HydrocephalusCare>

PROFILE

First Fogarty ophthalmology Fellow studies rare cancer

By Karin Zeitvogel

As the first Fogarty ophthalmology Fellow, Dr. Fran Lebajo Wu spent a year in Ethiopia, researching a rare pediatric eye cancer called retinoblastoma. Six months after diagnosis, more than half of children in Ethiopia with retinoblastoma die or are lost to follow-up, while in countries like the U.S., nearly all children with the cancer survive.

Wu worked with pediatric ophthalmologist Dr. Sadik Taju Sherief at Menelik II hospital in Addis Ababa—one of few facilities in the country of 107 million that provide care for children with retinoblastoma. As Wu analyzed data Taju had gathered from his retinoblastoma patients, she tried to tease out answers to numerous questions. How long after noticing the symptoms of the cancer did it take for parents to bring their children to the hospital? What treatment did a child receive? What were the outcomes for these young patients?

Her research also led Wu to wonder why Ethiopian children presented so late with retinoblastoma, what the follow-up and referral patterns of Ethiopian doctors were, and how having a child with the disease affected parents' mental health. To answer these questions, Wu launched several studies, including one in which she asked Ethiopian ophthalmologists what resources were available to them for diagnosing and treating retinoblastoma, and what their practice and referral patterns are. That study found wide variations in how the eye cancer is treated in Ethiopia and led to a project aimed at standardizing retinoblastoma care in the Horn of Africa country. Another study led by Wu found that caregivers of children with the cancer felt stigmatized and faced financial difficulties because of their child's illness. "At least one person said they had to beg for money in the streets just to be able to get an MRI for their child," Wu said.

Wu's research also shed light on why Ethiopian children with retinoblastoma often present with advanced-stage illness. Patients in whom the cancer is detected early can be treated with laser coagulation, but advanced retinoblastoma often requires surgery to remove the eye, followed by chemotherapy. "There are



Fran Wu, M.D., MPH

Fogarty Fellow: 2017-2018

Fellowship at: Addis Ababa University, Menelik II Hospital

U.S. organization: Emory University

Research focus: Retinoblastoma

kids in the U.S. whose retinoblastoma was caught early, who have 20-20 vision. I did not see many patients like that in Ethiopia," said Wu.

Interviews with Ethiopian parents found that while they often noticed the most common symptom of the cancer early—leucocoria, which is an abnormal white reflection from the retina of the eye—they either thought it wasn't abnormal and put off taking their child for treatment, or took their child to a health care provider "who did not understand that this needs referral and advanced treatment," said Wu. "That was a common story during our qualitative study—parents noticed it early but didn't get the appropriate treatment, even if they brought their child to a health care provider."

In addition to her research findings, Wu's Fogarty fellowship allowed her to lead a qualitative study and conduct research in a resource-poor country for the first time. She also helped to organize the first symposium on retinoblastoma in Ethiopia in May 2018. More meetings are being planned with the aim of "sharing how to build capacity and train more ophthalmologists and oncologists to treat this disease," said Wu.

Being a Fogarty Fellow not only allowed Wu to help improve care for retinoblastoma patients in Ethiopia but also taught her how to deal with the pitfalls and benefits of doing research in a resource-strapped country. "It confirmed for me that I want to work in global health, and that research needs to be part of what I do," she said. "Spending a year as a Fogarty Fellow in Ethiopia also gave me the vision and tools to seek or create for myself a research-focused role in a resource-poor setting and taught me how vital research is in building sustainable global health projects."

VONTHONAK SAPHONN, M.D., M.SC., PH.D.

Dr. Vonthanak Saphonn earned his medical degree in Cambodia at a time when the country, still recovering from war and genocide, was hit by HIV/AIDS. After working on an HIV surveillance program in Cambodia, he trained at the University of California, Los Angeles (UCLA) from 1999-2003 under a Fogarty program, becoming the first Cambodian to earn a Ph.D. in epidemiology. Returning home, he was named head of research at the National Center for HIV/AIDS, Dermatology and STIs and in 2007 founded the School of Public Health, which he led until his appointment as rector of the University of Health Sciences.



How has Fogarty affected your career?

Fogarty completely changed my career plan. After earning my medical degree, my dream was to become a pediatrician. But then I met Professor Roger Detels of UCLA in 1997 at a regional workshop he ran in Southeast Asia and became interested in epidemiology. In Cambodia prior to 2000, public health and research were very new and anyone who needed training had to go abroad. It's a big switch from clinical practice to public health, but Fogarty allowed me to study in the U.S. and successfully make the transition.

What are some of your career milestones?

I was inspired by the UCLA/Fogarty program to return to Cambodia and nurture the next generation of researchers. So after becoming the first Cambodian to earn a Ph.D. in epidemiology through the Fogarty program at UCLA, I returned home with big ambitions: I wanted to establish a school of public health in Cambodia. With the support of my mentors at UCLA and the network they connected me with, my mission was accomplished in 2007 when Cambodia's School of Public Health was opened, offering a master's of public health and a master's of science in epidemiology. As of today, we've trained more than 200 students.

I was dean at the School of Public Health until 2011, when I was transferred to the University of Health Sciences, where the Ministry of Health named me rector in 2012.

What skills did your Fogarty training give you?

My Fogarty training equipped me with leadership, critical thinking, and team-based problem-solving skills that prepared me to meet public health challenges. I also learned how to network and was exposed to research, and through the teaching assistantships I had at UCLA, I gained experience of working in an academic setting.

How important is reciprocity to your programs?

Reciprocity is very important, regardless of whether a

country is low- or high-income. Graduate students from the U.S. who want to go into global health come to Cambodia to study the large cohorts of patient populations with HIV, TB or malaria that we have here, and learn from our successes and challenges. For Cambodians, on the other hand, studying in the U.S. expands our horizons and minds. There are now three U.S.-trained Ph.D.s working at the School of Public Health in Cambodia, two of whom trained under the Fogarty program at UCLA.

What is your proudest achievement?

Fifteen years ago, Cambodia was 'famous' for having the highest HIV prevalence in the region. We had a lot of new infections, a lot of patients and no treatment. Today, Cambodia is 'famous' among Southeast Asian countries for a different reason—we've succeeded in significantly reducing the number of new HIV cases and, in 2017, UNAIDS recognized us for achieving the 90-90-90 target. This means 90 percent of Cambodians living with HIV know their HIV status, 90 percent of infected people are on antiretroviral therapy, and 90 percent of people on therapy have viral suppression. We are the only resource-limited country in Southeast Asia and one of just a handful of countries globally to achieve that goal. I am proud that the data on new and existing cases of HIV in Cambodia that my surveillance and research teams produced and analyzed were used by policymakers to plan and develop strategies to successfully combat HIV there.

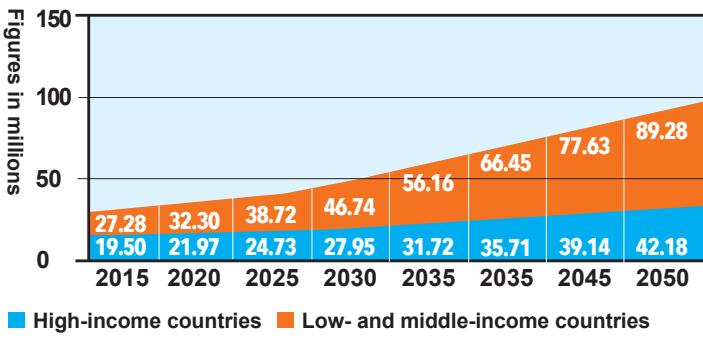
How did Cambodia reach the 90-90-90 goal?

A lot of stakeholders got involved, including the government and international partners. But without a visible, functioning public health institution, it would have been very difficult to get a commitment from the Cambodian government to be part of the fight. It's because we have such an institution and it had proven itself over the years that we were able to reach a challenging target like 90-90-90.

Tackling the growing, global burden of dementia

Every 3 seconds, somewhere in the world, there's a new case of dementia, according to Alzheimer's Disease International (ADI). One of the most burdensome conditions, dementia robs people of their memories, reasoning and independence and takes a staggering physical, emotional and financial toll on the individual, their family and society at large. Many experts are predicting a global epidemic that is expected to hit low- and middle-income countries (LMICs) particularly hard.

Global dementia is forecast to rise dramatically by 2050



Dementia is an umbrella term for several diseases that, for the most part, cause progressive changes in the brain that can affect thinking, behavior and the ability to perform even simple, everyday tasks. Alzheimer's disease, the most common form, is believed to account for 60-70 percent of all cases. Increasingly, evidence suggests a combination of genetic, lifestyle and environmental factors

Eldery women in Nigeria.

©2003 Shehu Danlami Sallihu, Courtesy of PhotoShare

influence the risk of dementia and how it progresses. With that, scientists are moving beyond a one-size-fits-all approach and are examining the heterogeneity of disease—how Alzheimer's and related dementias differ among individuals and across groups.

Researchers throughout the world are coming together to discover new or better interventions to delay, treat or prevent dementia. And they're studying how to support the wellbeing of family members who may experience anxiety, depression and other challenges as they tend to a loved one who needs round-the-clock care.

"This is a critical time in Alzheimer's research, with new opportunities to build upon what we have learned," said Dr. Richard Hodes, director of NIH's National Institute on Aging (NIA). Equipped with increased federal funding and guided by recommendations resulting from regular stakeholder summits, NIA is leading the U.S. government's research effort to prevent and effectively treat Alzheimer's and related dementias by 2025, a goal of the National Plan to Address Alzheimer's Disease, established in 2012. "We must continue to foster creative approaches that leverage emerging scientific and technological advances, establish robust translational infrastructure for rapid and broad sharing of data and research tools, and work with funding partners and other stakeholders to cultivate and sustain an open science research ecosystem."

NIH is supporting several international research collaborations to find treatment and prevention solutions, identify risk and protective factors, and collect comparable data that would enable analysis of worldwide trends.

Also, a number of research and capacity building projects in LMICs have been supported through Fogarty's brain disorders program, with funding from across NIH. To encourage more collaboration and coordination, NIA and the Alzheimer's Association developed a database of publicly and privately funded research around the world, the International Alzheimer's Disease Research Portfolio (IADRP).

Noting that only 15 percent of World Health Organization member states have a national plan to address dementia, WHO last year produced a global action plan that calls for a doubling of the output of global research on dementia by 2025.



Resources:

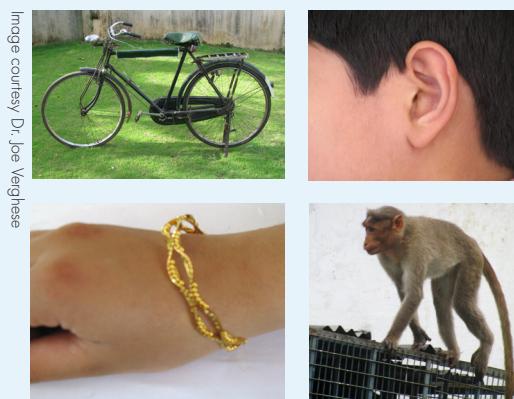
<http://bit.ly/AlzDementiaResearch>

Study in India sets stage for U.S. tests of screening tool

One of the challenges of screening for cognitive impairment, especially in low-resource settings, is accounting for varying levels of literacy and education, as well as cultural differences. To meet that need, NIH grantee Dr. Joe Verghese created a picture-based memory impairment screen (PMIS) that he validated in India and also has begun testing in the U.S.

While more sophisticated studies are required to officially diagnose dementia, this tool is a useful way to flag people who are having cognitive difficulties or may be at risk of impairment, said Verghese, a professor of neurology and medicine at Albert Einstein College of Medicine. The tool uses four pictures—each from a different category, such as animal or body part. People are asked to identify the images, associate each with a category and then recall the pictures. It's a four-minute test that non-specialists can administer.

Verghese is studying the PMIS in more than 300 people in Kerala, India through a National Institute on Aging (NIA) grant, funded under Fogarty's brain disorders program. He successfully demonstrated it could discriminate those with dementia from those without. The validated tool was later tested at a dementia center with a racially and ethnically



An NIH-funded study in India demonstrated a picture-based memory impairment screen could discriminate people with dementia from those without.

diverse population that Verghese runs in a New York City suburb. Researchers found it proved to be a reliable test that accounted for cultural, language and educational differences.

With another NIH grant, through a collaboration between the NIA and the National Institute of Neurological Disorders and Stroke, Verghese is studying a five-minute screen—dubbed the “5-cog”—to flag people who may have cognitive impairment so they can be referred for further evaluation. The screen will include a version of the PMIS and a test measuring how fast people walk. The latter evolved from his research validating motoric cognitive risk syndrome, in which older people develop a slower gait

and complain of memory loss, signaling they may be at risk for dementia.

“The idea is that somebody else in the office gives the test and then passes the results on to the physician, the same way blood pressure and heart rate are taken by a nurse,” explained Verghese. “If we can show this works, this would be one more thing that could be done before the patient actually saw the physician.

Brazilian brains focus of Alzheimer's genomics research



NIH grantees who've been conducting post-mortem studies of brains from donors in the U.S. are conducting a large study in Brazil to understand Alzheimer's in minorities.

its population is a unique mixture of African, European and Native Brazilian ancestry, and because it mandates autopsies be done on anyone who dies without a known cause.

To better understand Alzheimer's disease and how it differs between ethnic groups, NIH-funded scientists aim to conduct post-mortem analysis of 10,000 human brains donated for research in Brazil.

The country offers an unparalleled setting for the study because

U.S. investigators are collaborating with colleagues at the University of Sao Paulo to collect the brains and conduct the research. Located in Brazil's most populous city, the university houses a center that performs more than 13,000 autopsies a year, affording scientists a large pool of potential brains for research. Investigators will identify genetic variations that cause brain damage and dementia symptoms, which will greatly increase understanding of how these conditions affect blacks and Latinos, both in Brazil and the U.S.

“The opportunity in Brazil is extraordinary. There's no other place in the world where a study of this size could be accomplished,” according to Dr. David Bennett of Rush University Medical Center in Chicago, which has an \$11.2 million grant from NIH's National Institute on Aging to lead the Study of Ancestry, Neurodegenerative Diseases and Stroke (SANDS).

As dementia rises in Africa, urgent need for research

The aging population in sub-Saharan Africa poses an “impending crisis,” with the number of people with dementia expected to surpass 7.6 million by 2050. That forecast would be a 250 percent increase from current numbers, according to Alzheimer’s Disease International (ADI).

To curtail the growing burden of dementia that’s already costing the region an estimated \$6.2 billion each year, experts say there’s an urgent need to study possible risk factors and potential interventions.

“In Africa the prevalence will be climbing unless we do something about it,” said Dr. Adesola Ogunniyi, a professor at the University of Ibadan in Nigeria, who is involved in a Fogarty-supported training program. “We need to do more studies and focus on preventive strategies and then compare risks over time and see how this will pan out.”

Ogunniyi was a co-principal investigator on a long-term NIH-funded project that compared two groups of people of African origin living in different settings—African Americans in Indianapolis, Indiana and Yoruba in Ibadan, Nigeria. The longitudinal study ran from the early 1990s to 2012 and contributed some of the earliest evidence on the prevalence, incidence and risk factors associated with dementia in sub-Saharan Africa (SSA). Its findings of a lower burden of dementia among Yoruba compared to African Americans highlighted the significance of examining interactions between genes and the environment to better understand the condition.

Numerous studies from the project are among those cited in a 2017 ADI report *Dementia in sub-Saharan Africa: Challenges and Opportunities*, which provided a snapshot of the current situation, reviewed existing evidence and suggested areas for future investigation. More research is needed in almost all areas of the dementia field, the report concluded. It noted most of the evidence is coming from countries in central and western SSA, especially Nigeria, where the few longitudinal studies of potential risk and protective factors have been conducted.

RISK FACTORS MERIT FURTHER STUDY

Age and gender

Gender and increasing age are the risk factors that have been most closely associated with dementia in SSA. Studies found women have a two- to eight-fold increased



As the population ages, countries in sub-Saharan Africa need more dementia research to help curtail what’s described as an impending crisis.

risk of dementia, attributed to their longevity compared to men, as noted in the ADI report.

Genetics

Carrying a form of the apolipoprotein E (APOE) gene is known to increase the risk of Alzheimer’s disease among people in the U.S., but research in sub-Saharan Africa has produced mixed results. An early study from the Indianapolis-Ibadan project found the allele was not associated with Alzheimer’s disease in elderly Yoruba, while a later study with a larger cohort found it was. Studies by researchers in two other countries found no connection. Meanwhile, a novel mutation in another gene, presenilin 1, was found to cause familial, early-onset Alzheimer’s disease in South Africa, affecting 12 people spanning four generations of the same family.

Vascular disease

In the Yoruba study, elderly participants with high blood pressure had an increased risk of dementia, compared to people with normal readings. “Hypertension has stood out to be a convincing risk factor,” said Ogunniyi, noting that was a key contribution of the Indianapolis-Ibadan project. He led a study believed to be the first to examine hypertension and dementia in Africa. The risk was most significant with a systolic BP ≥ 160 or diastolic BP ≥ 90 . High cholesterol and peripheral artery disease also have been associated with dementia in other studies in the region.

Education and literacy

While education is considered a strong mitigating factor in high-income countries—with studies supporting the “cognitive reserve” hypothesis that education may impact onset of the symptoms of dementia—results in SSA are inconclusive. Some studies have found an association between low education and dementia, others found no interaction. When an association has been found, it’s often greater for women than men.

Early Life

Childhood circumstances such as birthweight and nutrition and their potential role in dementia have not been well-researched in SSA, according to the ADI report. A study in Central Africa found an association between losing a parent in childhood and dementia, but a later investigation found none.

Lifestyle and behavior

Diet, alcohol consumption and exercise—known to affect heart and brain health—are also being studied to see if they play a role in dementia. Yoruba Nigerians, whose traditional diet of grains, vegetables and fish is low-calorie and low-fat, were found to have lower cholesterol and a lower incidence of Alzheimer's disease compared to African Americans in a study from the Indianapolis-Ibadan project. An unrelated investigation in Nigeria examined cognitive impairment after stroke and found that a pre-stroke daily diet of fish and moderate-to-heavy physical activity were protective. Findings on the relationship between alcohol and dementia are mixed.

Psychosocial

Having a weak social network has been identified as a risk factor for dementia in SSA studies. Meanwhile, other research suggests Africa's traditional communal way of living, in which people are surrounded by family and friends, may have a protective effect by keeping the brain active. "This constant stimulation, we think, keeps brain synapses functioning and can reduce cognitive decline," said Ogunniyi, who reported on the finding as part of the Indianapolis-Ibadan project. He's now on a research team studying cognitive stimulation therapy, which uses group sessions with activities to stimulate and engage people who have mild to moderate dementia.

HIV dementia

Prevalence and risk factors of HIV-associated neurocognitive disorder (HAND) are being studied in SSA, but most of the research relates to young adults. Research in high-income countries (HICs) has shown long-term use of antiretroviral therapy is increasingly resulting in cognitive impairment and dementia, which is likely to be mirrored in SSA as the population living with HIV continues to age. Data on HAND in older Africans "is a current and urgent knowledge gap," according to the ADI report.

Photo by poco_bw/Stock/Thinkstock



Women living in sub-Saharan Africa are at greater risk of dementia than men.

Environment

While exposure to neurotoxins—such as copper, lead and aluminum—was not included as a possible risk factor in the ADI study, it was referenced in a Fogarty-led publication on brain disorders across the lifespan as an area that warrants more investigation. Many people living in developing countries experience significant air and water pollution, yet most of the work examining the possible relationship between cumulative exposure and onset of dementia has been done in HICs. There are unique opportunities to advance scientific understanding by conducting studies in SSA and other low-resource settings, the authors suggested. For example, many of the world's 14 million artisanal gold miners work in parts of Africa where there is little regulation and they are often exposed to high levels of mercury.

URGENT RESEARCH AGENDA

While researchers are forecasting a dramatic rise in dementia cases in SSA, public awareness and understanding of the condition in the region are low. Local languages may not even have a word for dementia and people may attribute symptoms to normal aging, or witchcraft, which could lead to stigma and discrimination.

To help SSA countries prepare for a rise in dementia cases as the population ages, the ADI report offers suggestions for an urgent research agenda. Studies estimating the prevalence and incidence of dementia should be a top priority and, when possible, designed to monitor incidence and mortality over time. Other suggested areas for future investigation include:

- The potential effect of genetic and modifiable risk factors that would support implementing risk reduction programs, policies and campaigns.
- The impact of the HIV/AIDS epidemic on dementia, particularly among older people.
- The experience of people with dementia and their caregivers as it relates to stigma, discrimination and seeking help.

"This report provides important evidence of the huge scale of the challenge we face on multiple fronts in sub-Saharan Africa," said Alzheimer's Disease International CEO Paola Barbarino. "Not only is dementia hidden socially, but governments must do more to enhance the infrastructure needed to support those affected."

OPINION

By Dr. Roger I. Glass, Director, Fogarty International Center

Encouraging research innovations that improve health



I find anniversaries can provide us with useful opportunities for reflection. As a diarrheal disease expert, I have recently been contemplating the impact of a research breakthrough that occurred fifty years ago—the discovery that oral rehydration therapy (ORT) could save thousands of people at risk of dying of cholera, for a treatment that cost just pennies to administer.

In 1968, a report from Bangladesh was published that described how oral rehydration solution (ORS) was used to successfully treat patients hospitalized in shock with cholera gravis, which untreated had a 40 percent mortality rate. Although research in the 1940s had demonstrated that administration of intravenous (IV) fluids was an effective approach, many cholera sufferers were located in low-resource settings where that was not available. For them, ORS was a miracle!

A few years later, at a cost of five cents each, UNICEF began producing and distributing packets of ORS that were to be added to a liter of water. Since 1968, the estimated number of childhood deaths from diarrhea has declined from about 5 million per year to about half a million.

In 1992, following years of debate about use of ORT in the U.S., the CDC recommended ORT should be the treatment of choice for all American children with diarrhea.

So what can we learn from this story of discovery that we could apply to other deadly diseases?

Sometimes the solutions are simple

Previous research had shown that sugar and salt mixed with water helped cholera patients. But it also killed some of them. The young scientists working in Bangladesh decided to measure the patients' output and use that as a basis to decide how much fluid to replace. That was the key to success.

Persistence in the face of failure

As I've learned in my rotavirus vaccine development career, setbacks are inevitable. By studying what went wrong, seeking advice from others and redoubling my efforts, I have managed to help produce some effective tools that prevent child deaths.

Necessity is the mother of invention

An American team of young physician-scientists found themselves in the unique setting of endemic cholera in the Ganges delta. People would literally die in front of them if the researchers didn't find an affordable, yet effective treatment. This wasn't a discovery made in a remote lab, it was made on the front lines of human suffering.

Optimism and fresh perspectives of youth

Established diarrheal disease experts knew ORS could be the answer but were perhaps intimidated by earlier failed clinical trials that resulted in some deaths.

Success breeds success

The 1968 article detailing the positive results was followed by a burst of research that increased the use of ORT for other diarrheal diseases and advanced new formulations that included zinc and encouraged feeding during diarrhea.

Oral rehydration therapy remains the mainstay of treatment for diarrhea worldwide for both adults and children and can be used by parents at home, as well as in clinics and hospitals.

Perhaps there are other simple treatments awaiting discovery that could prevent childhood deaths from other causes. I hope this story of success helps motivate some of today's young scientists. With the lives of so many children at stake, what better motivation can any of us have?



RESOURCE

<http://bit.ly/GlassORT>



Colleagues, collaborators mourn Mayosi

Professor Bongani Mayosi, a noted cardiologist and dean of the Faculty of Health Sciences at the University of Cape Town, died in July. His international research collaborations include serving as principal investigator with the Human Heredity and Health in Africa (H3Africa) initiative, managed by NIH's National Human Genome Research Institute and Fogarty. Mayosi's numerous honors include election to the U.S. National Academy of Medicine.



Top U.S. science advisor nominated

Dr. Kelvin Droegemeier has been nominated to head the White House Office of Science and Technology Policy and serve as the president's top science advisor. A meteorologist with a Ph.D. in atmospheric science, Droegemeier is Oklahoma's secretary of science and technology, and has been the vice president for research at the University of Oklahoma. He's served on the National Science Board, which provides guidance to the National Science Foundation, during the two prior administrations.



NIH announces new biomedical institute director

NIH has tapped Dr. Bruce J. Tromberg to lead its National Institute of Biomedical Imaging and Bioengineering (NIBIB), where he will oversee an annual budget of \$378 million. Tromberg comes to NIH from the University of California, Irvine, where he's held dual appointments in biomedical engineering and surgery. He has been the principal investigator on multiple NIH grants, including the Laser Microbeam and Medical Program (LAMMP).



Sizemore to lead Fogarty international relations

Dr. Christine F. Sizemore is the new director of Fogarty's Division of International Relations. Sizemore, who holds a Ph.D. in bacterial genetics and microbiology, began her NIH career at the National Institute of Allergy and Infectious Diseases where she most recently led its Tuberculosis, Leprosy and other Mycobacterial Diseases Section, and contributed to the development of numerous international collaborations. Prior to joining NIH, she worked in the pharmaceutical and biotechnology industry.



Nursing institute director Grady retires

After 30 years at the NIH, National Institute of Nursing Research (NINR) Director Dr. Patricia Grady has retired. Her NIH career began at the National Institute of Neurological Disorders and Stroke where she served as deputy director and acting director, before being tapped to lead the nursing institute in 1995. Her accomplishments include developing an intramural research program that improved understanding of fatigue in cancer patients and pain associated with digestive disorders.

New report examines global quality of care

Up to 8 million deaths occur each year from poor quality of care in developing countries—more than HIV, TB and malaria combined—according to a report published by the U.S. National Academies of Sciences, Engineering and Medicine. The study calls for more implementation science research and development of interventions to improve care.

Report: <http://bit.ly/NAMquality>

Study explores gaps in postdoc training

A landmark report identifies gaps in externally funded international postgraduate research training in Africa. While strengthening research capacity is recognized as a leading strategy to overcome health disparities worldwide, the study finds that support for research training is very unevenly distributed.

Report: <http://bit.ly/TDRAftraining>

Health policy and systems research studied

For health policy and systems research to remain relevant, its practitioners must re-think how health systems are conceptualized to keep up with rapid changes in how diseases are diagnosed and managed, according to a recent report published in the journal *Health Research Policy and Systems*.

Report: <http://bit.ly/HPSRreport>

NIH develops resource for behavioral trials

The NIH is requesting public comment on a draft Behavioral and Social Clinical Trials Template, created to guide investigators through the systematic development of a comprehensive clinical protocol. This is an expansion of the e-Protocol Tool.

Website: <http://bit.ly/NIHtemplate>

Free diabetes resource published online

A one-stop reference for medical information about diabetes has been published online by the NIH's National Institute of Diabetes and Digestive and Kidney Diseases. The publication contains prevention, treatment and other information.

Website: <http://bit.ly/DiabetesNIDDK>

FDA expands incentive program

The FDA has added Lassa fever, chikungunya, rabies and cryptococcal meningitis to a program designed to encourage development of new treatments. The initiative gives companies that develop drugs for certain tropical diseases a special pass to speed up the process for a future drug application.

Press release: <http://bit.ly/FDAropical>

Funding Opportunity Announcement	Details	Deadline
Emerging Global Leader Award - Career Development (K43)	http://bit.ly/GlobalLeaderOp	Nov 7, 2018
Global Brain and Nervous System Disorders Research across the Lifespan (R21 Clinical Trial Optional) (R01 Clinical Trial Optional)	http://bit.ly/globalbrainR21 http://bit.ly/globalbrainR01	Nov 7, 2018 Nov 7, 2018
Chronic, Noncommunicable Diseases and Disorders Research Training (D43 Clinical Trial Optional)	http://bit.ly/NCDtraining	Nov 13, 2018
International Research Scientist Development Award (IRSDA) (K01) Independent Clinical Trial Required Independent Clinical Trial Not Allowed	http://bit.ly/IRSDAct http://bit.ly/IRSDAnoct	Mar 7, 2019 Mar 7, 2019
Planning for Noncommunicable Diseases and Disorders Research Training Programs in LMICs (D71)	http://bit.ly/NCDlifespan	Mar 14, 2019

For more information, visit www.fic.nih.gov/funding

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Fogarty trainees in Dhaka collaborate on diarrheal diseases



Fogarty Director Dr. Roger I. Glass recently visited the labs at the icddr,b in Bangladesh and reviewed the research projects being conducted by Fogarty trainees. From left: Drs. Saruar Bhuiyan, Farhana Khanam, Yasmin Ara Begum and Glass.

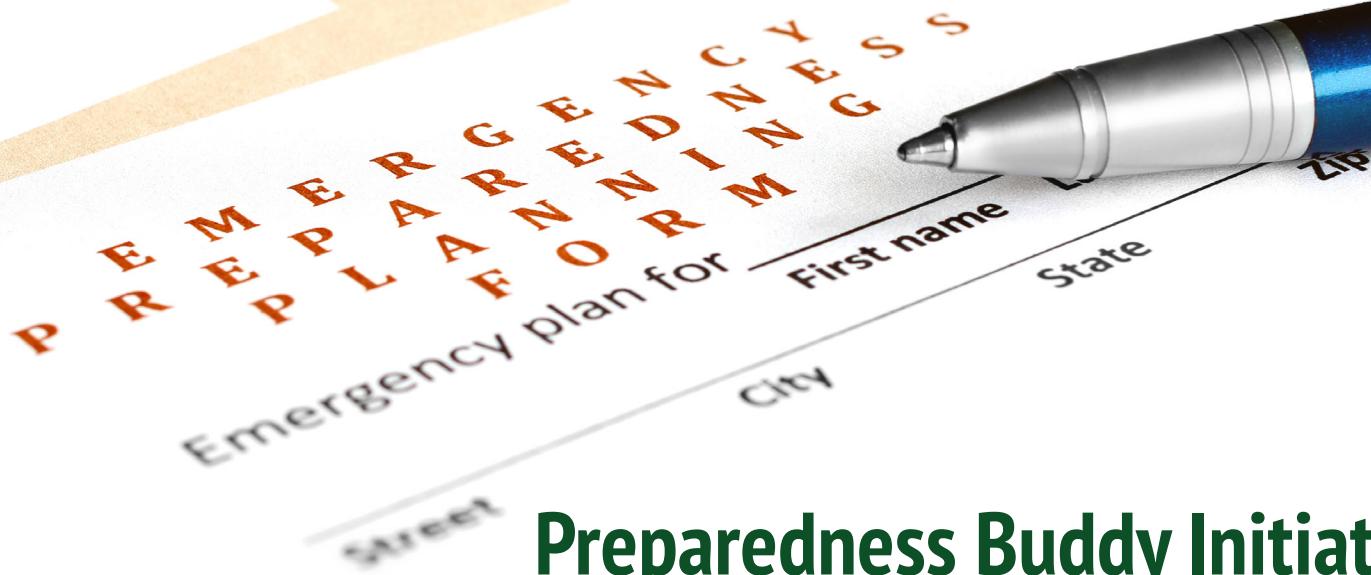
During a recent visit to Dhaka, Bangladesh, Fogarty Director Dr. Roger I. Glass had an opportunity to review the scientific projects being led by Fogarty trainees at the icddr,b.

"I was most impressed by the scientists I met who are working on research projects that are best done in Bangladesh, and helping to advance our knowledge of diseases that remain real killers of children and adults in endemic and epidemic settings—typhoid, cholera and diarrheal diseases in general," said Glass.

The researchers are working in partnership with investigators in the U.S. and elsewhere to share experiences, skills and collaborative research to improve diagnostics, vaccines and knowledge of diarrheal diseases.

RESOURCES

[https://www.icddrb.org/](http://www.icddrb.org/)



Preparedness Buddy Initiative Helps Vulnerable Delawareans Prepare for Emergencies

by Sean Dooley, Community Relations Officer, Delaware Division of Public Health

Hazardous weather events can occur suddenly and without warning, forcing Delawareans to shelter in place or evacuate. The Division of Public Health (DPH) recommends that Delawareans who live alone or have access and functional needs plan ahead and designate a “preparedness buddy” to help them plan for, and respond to, emergencies.

Preparedness buddies can help prepare a household emergency kit and an evacuation plan in case of fires, hurricanes, floods, extreme heat or cold events, snowstorms, and disease outbreaks. The buddy system ensures that vulnerable Delawareans have helpers, and that they have enough medication, oxygen, medical supplies, food, and water.

People with access and/or functional needs are those that have visual, hearing, mobility, cognitive, emotional, or mental limitations. They may need help maintaining independence, communicating, and getting medical care and taking their medications. They may need supervision and might rely on translation, sign language interpreters, or transportation services. People with access and/or functional needs should ask someone dependable to

serve as their preparedness buddy and another to be their alternate buddy.

DPH’s Preparedness Buddy brochure, available at <http://www.dhss.delaware.gov/dhss/dph/php/preparednessbuddy.html>, is an important tool to get started. The brochure is available in seven languages: English, Spanish, French Creole, Vietnamese, Simplified Mandarin, Traditional Cantonese, and Brazilian Portuguese. The brochure’s step-by-step template makes it easy to develop a personalized emergency plan in case individuals must evacuate or shelter in place.

The Preparedness Buddy brochure includes a list of essential emergency items: drinking water, food, eyeglasses, flashlights, wheelchairs, hygiene items, a first-aid kit, and important documents. It provides spaces on which to list the primary care physician, allergies, medication and supplies, and transportation requirements.

Buddies can include in the personal emergency plan what to do in case of interrupted utilities (electricity, gas, phone, and garbage disposal) and interrupted

transportation (medication deliveries, transportation to and from work, and caregiver and family visits). Home health care clients should contact their providers to ask how bad weather impacts their schedule and their ability to reach clients. Include contact names, street addresses, phone numbers, and email addresses. It is important to review and update emergency plans each year or during peak disaster seasons.

A helpful resource for completing the brochure is the “Emergency Preparedness” section of the Guide to Services for Older Delawareans and Persons with Disabilities at <http://www.delawareadrc.com/>, pages 82 to 84. Also read the emergency planning instructions for your region:

- New Castle County Emergency Operations: 302-395-2700 or <http://nccde.org/154/Emergency-Management>
- Kent County Emergency Operations: 302-735-3465 or www.co.kent.de.us/public-safety/emergency-management.aspx
- Sussex County Emergency Operations: 302-855-7801 or www.sussexcountyde.gov/emergency-operations-center

Finally, register Delawareans with access and functional needs with the Smart 9-1-1 website: <https://www.smart911.com/>. Smart 9-1-1 is a service that allows residents to create a free household safety profile that 9-1-1 and first responders can use during an emergency. It is in a secure database held by SMART 911 which is accessible only after a call is placed and for a limited timeframe. Whenever anyone in a Smart 9-1-1 household dials 9-1-1 from a phone associated with the profile, it is displayed to the 9-1-1 call taker. All three counties use Smart 9-1-1.

The screenshot shows the Smart911 website homepage. At the top, there are "SIGN UP" and "SIGN IN" buttons. Below that, a green banner says "Plan Ahead For Any Emergency". A subtext below the banner reads "Give 9-1-1 the information they need to help you fast." A "SIGN UP TODAY" button is prominently displayed. Below this, a note states "Smart911 protects over 45 million people nationwide." Three circular icons represent different features: "Safety Profile" (green), "Alerts and Notifications" (blue), and "Vulnerable Needs Registry" (orange).

For more information on items to keep in a disaster kit and evacuation planning, visit:

- www.Preparede.org - The State’s central site for emergency planning and preparedness, created jointly by the DPH Emergency Medical Services and Preparedness Section, the Delaware Emergency Management Agency, and the Delaware Citizen’s Corps.
- www.Allreadyde.org - The University of Delaware’s webpage for Emergency Readiness Planning for Delawareans with Disabilities.
- www.Ready.gov – The Federal Emergency Management Agency’s planning site for individuals with disabilities and others with access and functional needs.
- The American Red Cross’s People With Disabilities planning page, <http://www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities#Plan-Ahead>. The website includes how to assemble a survival kit and offers additional tips about managing communications, equipment, service animals, pets and home hazards.

References

American Red Cross — <http://www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities#Plan-Ahead>

Division of Public Health, press release, “DPH Shares ‘Preparedness Buddy’ Brochure to Help Delawareans Prepare for Emergencies,” http://www.dhss.delaware.gov/dhss/pressreleases/2017/preparedness_02172017.html

Division of Public Health – Preparedness Buddy brochure, <http://www.dhss.delaware.gov/dph/php/preparednessbuddy.html>

PrepareDE.org — <http://www.preparede.org>



*Sean Dooley, Community Relations Officer,
Delaware Division of Public Health*

The image shows a grid of six cards, each featuring the "PREPAREDNESS BUDDY" logo. The cards are arranged in two rows of three. The top row contains cards in English, Spanish, and Vietnamese. The bottom row contains cards in Chinese, Korean, and Japanese. Each card has a small logo of a person holding hands at the bottom. Below the cards, there is explanatory text in English and other languages.

Plan de Mi re E d Ofic	Plan Kadi Rezo Sou Kalite Sistem Biwo Prep	Kế hoạch cá Hệ thống Hình thức h Văn phò	Plano de Estilo do da re	我的个人 个 个	Your Name Personal Emergency Plan My Personal Support Network Buddy System Style Office of Preparedness: 302-223-1720
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Increasing Access to Empirically-Validated Interventions for Autism Spectrum Disorder: Dissemination of PEERS into Community Health Settings



Laura Dewey, Ph.D.
Cathy Rose, L.P.C.M.H.
Jessica Mueller, Psy.D.
Brianna Spencer, B.A.
Brian Freedman, Ph.D.

Abstract

Objectives: This research project aims to build capacity for social skills interventions for ASD for adolescents in community mental health settings in Delaware, using The Program for the Education and Enrichment of Relational Skills (PEERS), a social skills group program developed at UCLA (Laugeson and Frankel, 2010).

Methods: Aim 1: A two-day education on PEERS was provided to community clinicians ($n=15$), and clinicians completed a survey assessing their perception of implementing a social skills group intervention for families at three time points. Aim 2: Five PEERS groups were held at three community mental health locations. Caregivers ($n=14$) completed rating scales assessing family quality of life, social skills, or parenting stress.

Results: Clinicians reported increased confidence in their ability to deliver social skills intervention following two-day education on PEERS. Furthermore, the clinicians who facilitated a PEERS group ($n=9$) reported a clinically significant increase in confidence. Fourteen families completed PEERS; no difference was reported regarding family quality of life, social skills, or parenting stress.

Conclusions: This study shows the feasibility of expanding social skills interventions for children and families affected by ASD into community mental health settings, as 15 clinicians received additional education regarding social skills interventions and five more group opportunities using the PEERS program were made available in the community.

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder marked by significant impairment in social communication and interaction and the presence of restricted, repetitive patterns of behavior and interests. At the present time, it is estimated that approximately 1 in 59 children have a diagnosis of ASD in the United States (CDC, 2018). ASD is also commonly associated with other conditions such as intellectual disability (ID) and other mental health comorbidities such as anxiety, depression, obsessive-compulsive disorder (OCD), and attention-deficit/hyperactivity disorder (ADHD; McClintock, Hall, & Oliver, 2003). Thus, individuals and families affected by ASD often experience daily functional challenges.

Social skills groups have been found to be one way to teach social skills to individuals with ASD. In one meta-analysis, Reichow, Steiner, and Volkmar (2013) found that individuals with ASD who participated in a group-based social skills intervention reported less loneliness and an increase in social competence and quality of friendships than those individuals with ASD who did not participate in a social skills group. Many studies have shown that group social skills interventions are effective for adolescents with ASD in that group settings serve as an in vivo opportunity to practice new skills (White, Keonig, & Scahill, 2007). Researchers have shown that teaching both basic and more complex social skills in a group context has been supportive of both improved relationships and quality of life (QoL) for adolescents with ASD and their families (Rankin, Weber, Kang, & Lerner, 2016). With an increase in social skills, adolescents with ASD are more able to effectively communicate their needs and desires, as well as attend to the needs and desires of others, including their peers and other family members (Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012). Adolescents also benefit from an increase in social skills development in school with teachers as well as in employment situations (Cappadocia and Weiss, 2011).

One program that has been particularly effective in teaching social skills to adolescents with ASD is the UCLA Program for the Education and Enrichment of Relational Skills (PEERS; Laugeson and Frankel, 2010; Haddad, 2013). The PEERS intervention intends to improve social skills of adolescents with ASD and support caregivers in helping their adolescent navigate novel social experiences like calling a friend or joining a new peer group. PEERS is unique because it emphasizes ecologically-valid skills, role playing between group leaders and participants, practicing of skills in session, and homework assignments that are facilitated by caregiver involvement. Research indicates that basic

social skills development programming increases relationship satisfaction among adolescents with ASD and their caregivers (Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012; Haddad, 2013; Chang et al., 2014) and that increased

functioning in children and adolescents with ASD leads to a positive increase in overall family functioning (Haddad, 2013).

Community Engagement Plan in Delaware

A recent needs-assessment of families affected by ASD in the state of Delaware identified a critical need for social skills interventions among caregivers of children with ASD (Rhoton & Ekbladh, 2012; University of Delaware, 2013). Furthermore, this needs-assessment also highlighted the dearth of all services for families affected by ASD in Southern Delaware. At the time of the study, the PEERS social skills group program was available to families in an outpatient hospital clinic (at Nemours/AIDHC in Wilmington, DE) and in select school districts across the state. However, opportunities for social skills group interventions for ASD in the community were rare, not based on an empirically-validated programs, and restricted primarily to northern parts of the state.

The ACE Research Awards of the Delaware-CTR ACCEL program, a partnership between the University of Delaware and Delaware institutions, offered a unique opportunity to take an existing evidence-based practice (the PEERS program for families affected by ASD) and disseminate this program into the community. This undertaking involved the engagement of several community partnerships: Dr. Dewey as the academic investigator from Nemours/AIDHC, Ms. Rose as the community investigator from Delaware Guidance Services for Children and Youth, Inc (DGS), Dr. Freedman as mentor from the University of Delaware, and Autism Delaware as a source of study recruitment and support.

UCLA PEERS® Clinic

Social Skills Group For Adolescents

PEERS® for Adolescents is a 16-week evidence-based social skills intervention for motivated teens in middle and high school who are interested in learning new ways of making and keeping friends. This internationally acclaimed program, used in over 35 countries, was originally developed at UCLA by Dr. Elizabeth Laugeson. During each group session, teens are taught important social skills and are given the opportunity to practice these skills in session during socialization activities. Parents attend separate sessions to receive training and learn how to support their teen's learning and make new friends by helping to expand their teen's social network while providing feedback through weekly socialization homework assignments. PEERS® may be appropriate for teens with Autism Spectrum Disorder, ADHD, Anxiety, Depression or other social and behavioral disorders. Parent participation is required.



Teens will learn how to:

- Use appropriate conversational skills
- Use humor appropriately
- Use electronic communication
- Enter & exit conversations
- Be a good host during get-togethers
- Be a good sport
- Handle arguments and disagreements
- Change a bad reputation
- Handle rumors and gossip
- Handle rejection, teasing and bullying

For enrollment information, please contact (310) 26-PEERS (310-267-3377) or email: peers@ucla.edu

For more information, please visit our website at www.semel.ucla.edu/peers [@UCLAPEERS](https://www.facebook.com/uclapeers) [@UCLAPEERS](https://www.instagram.com/uclapeers)



Study Aims

The aims of this study were twofold; Aim 1: Build capacity for ASD interventions by providing formal education to community clinicians at DGS in PEERS; and Aim 2: Assess parent perspectives following participation in PEERS regarding social skill symptoms, parenting stress, and family QoL. This project explored the feasibility of disseminating PEERS into community mental health settings by assessing community clinician's perceptions of implementing PEERS prior to formal two-day education, after the education, and again following PEERS intervention. Additionally, this project expanded on the current research by using measures aimed to assess caregivers' parenting stress and QoL, in addition to perceived social skills improvement, at baseline and following the PEERS intervention.

Method

Aim 1: Build capacity for ASD interventions by providing formal education to community clinicians in PEERS

The first part of the study design involved educating community mental health clinicians on implementation of PEERS. The clinical director at DGS identified clinicians interested in expanding their clinical competency on ASD and providing social skills interventions from the agency's five locations across the state of Delaware; these clinicians hold at a minimum a master's degree in a mental health field. A two-day formal education in PEERS for these clinicians ($n=15$) was held at the DGS location in Dover, a central location in the state. The education included an overview of ASD and adolescence led by the study authors, as well as instruction on using the PEERS manual led by a University of Delaware instructor who also disseminated PEERS into school-based settings. Support was provided to the clinicians regarding logistics as well, such as considerations when recruiting participants, information to be provided to families, and billing/documentation to support sustainability. In order to understand the feasibility of successfully holding PEERS in the community, clinicians completed a survey developed by the researchers three times over the course of the study: prior to the two-day education, after the two-day education, and following PEERS group completion

(see Appendix A). Prior to the beginning of PEERS education, the study was explained to the clinicians and written informed consent was obtained.

Implementation of PEERS

After the two-day education in PEERS, two sets of PEERS groups were conducted: Set A consisted of three PEERS groups held at three DGS sites (Seaford, Lewes, and Dover); Set B consisted of two PEERS groups held at two DGS sites (Lewes, Seaford) conducted following completion of Set A. The reduction from three sites to two sites occurred due to attrition of the clinicians trained in PEERS. Each PEERS group was held for one-hour, once a week, for 14 weeks in the evenings. Two clinicians ran the adolescent group in order to role-play social skills, and one clinician ran the concurrent parent group. Topics covered included: trading information, two-way conversations, electronic communication, choosing appropriate friends, appropriate use of humor, entering a conversation, exiting a conversation, get-togethers, good sportsmanship, teasing and embarrassing feedback, bullying and bad reputations, handling disagreements, rumors and gossip, and graduation and termination. Families that participated in 11 of the 14 sessions were considered to have completed the treatment. At each of the first sessions, clinicians explained the study to the adolescents and their caregivers; written informed consent from the caregivers and written assent from the adolescents was obtained.

Aim 2: Assess parent perspectives following participation in PEERS regarding social skill symptoms, parenting stress, and family QoL.

The second part of the study aimed to understand the impact of the PEERS group on caregivers' perspectives of social skills improvements and family functioning. The participants were the caregivers of adolescents with ASD recruited from the community by flyers distributed by Nemours/AIDHC, DGS, and Autism Delaware. Inclusion criteria included caregivers of individuals with a historical diagnosis of ASD and evidence of average language and cognitive ability (based on either school/medical records or clinician judgment) between the ages of 10 and 18. Exclusion criteria included non-English speaking families. In total, five PEERS groups were held at three DGS locations across the state of Delaware. Thirty families enrolled in PEERS (age range of child: 10-17; M=13 years; Males=23, Females=7), and 14 families were considered to have completed PEERS (attended 11 or more sessions and the same caregiver

completed both pre and post measures). Caregivers (n=14) completed: 1) Social Responsiveness Scale, Second Edition (SRS-2; Constantino & Gruber, 2012; to measure social skills); 2) Stress Index of Parents of Adolescents (SIPA; Wu, 2017; to measure parenting stress); and 3) Beach Center Family Quality of Life Scale (FQOL; Beach Center on Disabilities, 2006; to measure family quality of life).

Results

Regarding dissemination, this research study allowed for 15 community mental health practitioners to gain increased competency in understanding and supporting families affected by ASD as well as concrete training on the implementation of empirically-validated social skills interventions. These clinicians serve communities across the state of Delaware, and it is hoped that this opportunity positively influences their clinical practice.

The first aim of this study sought to understand the impact of the two-day education on PEERS on clinician's confidence in delivering social skills group intervention, based on their ratings on a Likert Scale questionnaire developed by the researchers. Results showed that clinicians (n=14) reported increased confidence in their ability to deliver social skills intervention following two-day education on PEERS, as rated on a Likert Scale with 0 being no confidence and 5 being most confidence (pre: M=3.2, SD=1.3; post: M=4.1, SD=.9; $t(14)=-2.82$, $p=.014$). Furthermore, the clinicians who facilitated a PEERS group (n=9) reported a clinically significant increase in confidence ($t(8)=-2.309$, $p=.05$) from post education to post facilitation of a PEERS group.

The second aim of this study sought to expand understanding of parent perceptions on changes in social skills, family quality of life, and parenting stress pre- and post-PEERS participation. Given the attrition of families, there was a small sample size (n=14). Results showed that no difference was reported regarding parent perception of family quality of life (FQOL: $t(13)=-.737$, $p=.474$), social skills (SRS-2: $t(11)=-1.183$, $p=.261$), or parenting stress (SIPA: $t(11)=.549$, $p=.594$).

Discussion

This study extends the evidence base for social skills interventions from hospital and school-based settings to community mental health clinicians. Primarily, this project explored the impact of formal education on PEERS for clinicians implementing this intervention.

Second, this project assessed the possibility of changes in parent stress, family quality of life, and perception of social skills changes after participation in PEERS. Furthermore, this project allowed for the formation of novel and innovative partnerships between Nemours/ AIDHC, DGS, the University of Delaware, and Autism Delaware. These organizations each contribute valuable knowledge of the research and treatment for mental health difficulties that affect children and families.

Given the results, this study shows the feasibility of expanding social skills interventions for children and families affected by ASD into community mental health

settings, as 15 clinicians received additional education regarding social skills interventions and five more group opportunities using the PEERS program were made available in the community. Although the PEERS program did not show changes in parental perception of family quality of life, adolescent's social skills, or parenting stress, the study was limited by a small sample size of 14 families completing the intervention. Future research is needed to understand family characteristics and barriers that may impact completion of social skills programs in the community.

Successes

This research study allowed for the formation of novel partnerships and increased community engagement around the ASD population in Delaware. The willingness of community agencies to be involved in opportunities to increase clinical competencies for ASD and serve families affected by ASD across the state was



Delaware Guidance Services

for Children and Youth, Inc.

inspiring; DGS and Autism Delaware recognized the need to increase opportunities for social skills and proved willing and able partners. Nemours/AIDHC and the University of Delaware gained greater understanding of the challenges associated with real-world implementation of empirically-validated interventions, such as billing and insurance restrictions, time and questionnaire burdens on families, and ways to successfully communicate with community partners.

It is a testament to the strength of Delaware's collaborators in the ASD community that made this research study a success; Delaware gained several more clinicians willing and able to provide social skills interventions for ASD in communities where the need is the greatest, such as in Southern Delaware. At least one PEERS group is still being held at DGS in Southern Delaware at the time of this publication.

Lessons Learned

This research study also illuminated future opportunities to make community-engaged research a success. First, it is critically important to have a champion identified in the community who is able to push the cause forward; without leadership support from DGS, there would have been numerous insurmountable burdens preventing the clinicians from taking part in a two-day training and creating a new program (e.g., work requirements, billing difficulties, space identification, etc.). Second, ongoing consultation or coaching through the learning and implementation of empirically-validated interventions is critical; no formal ongoing consultation was provided as part of this study, but it may have prevented attrition, helped to problem-solve barriers to family attendance, increased the support available, and provided additional opportunities for ASD-related learning. Follow-up coaching following training has proven successful to increase fidelity of the intervention and outcomes for evidence-based practices in working with children with ASD (Kucharczyk, Shaw, Smith Myles, Sullivan, Szidon, & Tuchman-Ginsberg, 2012). Third, the community mental health field is transient; though 15 clinicians were originally trained in PEERS, six clinicians had left DGS by the end of the study. This poses challenges in planning for the pre- and post data needed for empirical research studies.

Last, the sample size in this study was small, both in terms of the numbers of clinicians trained and the number of families who participated. Though it represents a success in terms of increased community engagement in utilizing empirically-validated interventions for ASD, it creates a challenge for ongoing empirical research. There are numerous family barriers that need to be better understood and considered when embarking on a research study to expand empirically-validated interventions; these interventions might work well in a grant-funded academic institution, but in the community they might not be feasible. One burden on both families and institutions is that of insurance issues; insurance may not cover the cost of social skills groups, and reimbursement for the clinicians may be minimal. Furthermore, families of children with ASD are often burdened with transportation, child care, and financial responsibilities that prohibit consistent participation in a structured, one-hour a week time commitment lasting several weeks. These considerations highlight the need to consider how to adapt and modify interventions to meet the realities of families in real world, community settings.

Overall, results of this study support the continued collaboration between medical centers, universities, and community partners to extend evidence-based practices into the community. This project enabled evidence-based interventions currently utilized in medical and school settings to become more readily available to families impacted by autism spectrum disorder. The education and support of a community mental health agency in the needs of a unique, specialized mental health population will result in increased access to specialized mental health services. As rates of ASD grow in the United States (CDC, 2018), this sort of specialized training in community mental health agencies is essential for establishing competent care for those typically underserved in communities.

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Not Shown:

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Appendix A: Clinician Surveys

Clinician Survey – Pre PEERS Education

1. How confident do you feel in understanding the symptoms of Autism Spectrum Disorder (ASD)?

1	2	3	4	5
None				Very

2. How confident do you feel in treating ASD?

1	2	3	4	5
None				Very

3. How confident are you that you can effectively deliver social skills groups for ASD?

1	2	3	4	5
None				Very

4. How confident are you that social skills groups for ASD result in improvements for children and families?

1	2	3	4	5
None				Very

5. How satisfied are you with the current interventions you use for ASD?

1	2	3	4	5	N/A
None					Very

6. What are you hoping to learn from the education in PEERS?

Clinician Survey – Post PEERS Education

1. How confident do you feel in understanding the symptoms of Autism Spectrum Disorder (ASD)?

1 2 3 4 5
None  Very

- ## 2. How confident do you feel in treating ASD?

1	2		3	4	5
None	Some	Many	Most	All	Very

3. How confident are you that you can effectively deliver social skills groups for ASD?

1	2	3	4	5
None				Very

4. How confident are you that social skills groups for ASD result in improvements for children and families?

1	2	3	4	5
None				Very

5. How satisfied are you with the current interventions you use for ASD?

6. How much do you believe the PEERS education improved your understanding of ASD?

7. How much do you believe the PEERS education improved your interventions skills for ASD?

1	2	3	4	5
None	Some	A lot	A great deal	Very

8. How confident are you in using PEERS moving forward?

9. What do you think will be helpful aspects of PEERS in your setting? Check all that apply.

- structured program
- didactics for adolescents
- opportunity for adolescents
- caregiver participation
- other

10. What do you think will be barriers to using PEERS in your setting? Check all that apply.

- Program is too structured
- Adolescents will not benefit from didactics
- Adolescents will not interact with each other
- Families will not attend consistently
- Other

11. What was most helpful about the PEERS education?

12. What would you change about the PEERS education?

Clinician Survey – Post PEERS Intervention

1. How confident do you feel in understanding the symptoms of Autism Spectrum Disorder (ASD)?

1 2 3 4 5
None Very

2. How confident do you feel in treating ASD?

1 2 3 4 5
None Very

3. How confident are you that you can effectively deliver social skills groups for ASD?

1 2 3 4 5
None Very

4. How confident are you that social skills groups for ASD result in improvements for children and families?

1 2 3 4 5
None Very

5. How satisfied are you with the current interventions you use for ASD?

1 2 3 4 5 N/A
None Very

6. How much do you believe the PEERS education improved your understanding of ASD?

1 2 3 4 5
None Very

7. How much do you believe the PEERS education improved your interventions skills for ASD?

1 2 3 4 5
None Very

8. How confident are you in using PEERS moving forward?

1 2 3 4 5
None Very

9. What do you think will be helpful aspects of PEERS in your setting? Check all that apply.

- structured program
 didactics for adolescents
 opportunity for adolescents to interact
 caregiver participation
 other _____

10. What do you think will be barriers to using PEERS in your setting? Check all that apply.

- Program is too structured
 Adolescents will not benefit from didactics
 Adolescents will not interact with each other
 Families will not attend consistently
 Other _____

11. How likely are you to use PEERS in the future?

1 2 3 4 5
None Very

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A Stroke Reduction Health Plan for Older Adults in Rural Sussex County, Delaware

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Mary Elizabeth Bowen, Ph.D.
Mari Griffioen, Ph.D., R.N.

Abstract

Stroke is a leading cause of death and disability among adults age 65 and over in the United States. Modifiable risk factors for stroke include: obesity, poor nutrition, and lack of exercise. Sussex County, Delaware has the highest stroke rate among older adults in the state. Twenty-five percent of the population in Sussex County are 65 and over and about 70% of adults are overweight or obese. Consistent with the social ecological framework, the Stroke Population Risk Tool may be used at the individual level to identify those at an increased risk for stroke and to create individualized stroke specific education. At the community level, local nutrition, fitness, and senior services may be utilized - with older adults at the highest risk profile participating in a 12 week stroke education program focused on risk reduction behaviors, nutrition and exercise classes. At the policy level, the Walkability Assessment Tool may be utilized to encourage local municipalities to identify areas of the county which lack safe spaces to be physically active and to develop a plan to create a more exercise conducive environment. Taken together, the proposal discusses an implementable plan that may, in the long-term, effectively reduce the stroke rates of older adults in Sussex County and allow for the early identification of those at the greatest risk for stroke.

Introduction

Cerebrovascular accidents (CVA) are the fifth leading cause of death in the U.S., associated with long-term disability and over \$34 billion in health care costs (Benjamin, 2015). Though an estimated 80% of strokes are preventable, about 800,000 new or recurring strokes occur every year (Yang et al., 2017). Deaths from stroke were declining, but the rate of decline has slowed in recent years with an uptick in deaths in 2013. This may be due to increases in life expectancy, obesity, reduced health care access, as well as an unhealthy diet, and physical inactivity (Yang, 2017).

Over 25% of the population in Sussex County, Delaware is over the age of 65 (US Census Bureau, 2016). Delaware is an attractive location for retiring baby boomers and other older adults with low overall tax rates, a central location and tourist attractions such as beaches (Delaware Division of Public Health, 2016). By 2040 there is a projected increase of more than 50% in the 65 and older population (Delaware Division of Services for Aging and Adults with Physical Disabilities, 2016). Among the oldest old (age of 85 and over), population growth is expected to double to more than 18,000 individuals by 2040 (Delaware Division of

Services for Aging and Adults with Physical Disabilities, 2016). The risk of stroke increases exponentially with age; stroke prevalence is about 5.7% in 60-79 year olds and 14-15.5% among adults age 80 and over (National Health and Nutrition Examination Survey, 2009-2012).

In addition to age, other primary risk factors for stroke are diabetes, hypertension and hyperlipidemia (Romero, Morris, & Pikula, 2008). Compared to their older adult counterparts in other areas of the state, Sussex County has the largest population of obese and overweight adults with elevated rates of diabetes (28.2%), hyperlipidemia (64.8%), and hypertension (64.2%) (Delaware Health Tracker, 2017). Older adults in Sussex County also have lower physical activity rates (with fewer than half of residents reporting regular exercise) and poorer nutrition (26.5% consume recommended daily servings of fruits and vegetables) (Delaware Health Tracker, 2017). This may be due, in part, to fewer opportunities for exercise, an increase in fast food restaurants across the county, and a decrease in grocery stores supplying fresh fruits and vegetables (Delaware Health Tracker, 2017).

Access to quality health care may also be a barrier for some older adults in the county. About 20% of communities in the US are rural, but fewer than 10% of physicians practice in rural areas (Periyakoil, 2010). As a designated Health Professional Shortage Area (HPSA), Sussex County has over 3,500 people per primary care provider (PCP). Of those, 67.5% accept new Medicare patients which equates to an average 17 day wait time for an established patient and a 45 day wait time for a new patient (Delaware Division of Public Health, 2016). Some older adults also have limited access to reliable transportation. Rural populations must travel greater distances to reach healthcare facilities, particularly specialists, and there is often inadequate public transportation (Periyakoil, 2010). In a community health survey of the three hospital systems in Sussex County, lack of reliable transportation was repeatedly highlighted as a considerable barrier to healthcare (Delaware Division of Public Health, 2016). Access to quality healthcare is associated with access to clinical preventative screenings and services and overall improved mortality (Healthy People 2020, 2017). Thus, reduced access to care puts patients at an increased risk for stroke.

Given these individual, community and policy-level factors influencing stroke risk and access to quality health care among older adults in Sussex County, this paper utilizes a social ecological framework to begin to develop a tailored health plan for Sussex County,

Delaware. Consistent with current work emphasizing the need for increased collaboration between public health policy and community level resources to combat the multilevel factors contributing to chronic disease, this paper provides recommendations for multi-level interventions which may be used to effectively reduce the risk for stroke in the local community (Rattay, Henry, & Killingsworth, 2017).

Health Plan

Using the ecological perspective as a framework, the primary outcome of this health plan is to decrease stroke prevalence from 5.5% to less than the national

average of 4% within 5 years (Delaware Health Tracker, 2017). As outlined in Table 1, this will require that we target seniors at the highest risk for stroke and establish a successful health plan that integrates individual, community, and policy-level factors and promotes healthy behaviors by the use of a 12-week stroke risk prevention program, improved nutrition, and increased physical activity.

Outcomes

The individual level outcomes are to: 1) identify individuals at an increased risk of stroke using the Stroke Population Risk Tool (SPoRT), 2) institute

Table 1. Stroke reduction plan for Sussex county. Note: SPoRT= Stroke Population Risk Tool

	Individual Level	Community Level	Policy Level
Outcome	<ol style="list-style-type: none"> Identify individuals at highest risk for stroke. Institute individualized, patient focused stroke risk reduction health plan. Refer individuals at risk of stroke to appropriate community resources. 	<ol style="list-style-type: none"> Establish a 12-week stroke risk reduction workshop. Improved nutrition by improving access to healthy foods among seniors. Improved physical fitness among seniors. 	<ol style="list-style-type: none"> Determine environmental factors impeding access to physical activity and nutritious foods. Improve the utilization of public areas for walking and exercise.
Performance Measure	<ol style="list-style-type: none"> Number of individuals screened for stroke using SPoRT. Number of individuals participating in stroke risk reduction health plan. Number of individuals referred to community-based activities. 	<ol style="list-style-type: none"> Number of individuals participating in 12-week stroke risk reduction workshop. Number of individuals participating in community-based nutrition programs. Number of individuals participating in physical fitness classes. 	<ol style="list-style-type: none"> Number of Sussex municipalities using the Walkability Assessment Tool.
Strategy/Tactics	<ol style="list-style-type: none"> Use of SPoRT to identify individuals at risk for stroke. Develop individualized stroke risk reduction health plan. based on SPoRT score. Provide individuals with a list of community resources available. 	<ol style="list-style-type: none"> Initiate a 12 week education workshop comprised of stroke education on risk factors and behavioral risk reduction strategies, nutrition* and exercise** interventions. <p>*Nutrition interventions include: (a) establish a community-based senior nutrition program, (b) weekly nutrition classes focused on a low sodium, low cholesterol, well balanced diet; simple meal preparation; healthy food samples; and where to obtain fresh ingredients, (c) referrals to meal delivery services (Meals on Wheels, local grocery delivery services, mobile grocery stores).</p> <p>**Exercise interventions include: (a) 20-50-minute choreographed exercise sessions three time a week, (b) referrals to community fitness centers and exercise programs offered at local senior centers.</p> <ol style="list-style-type: none"> Continued follow up with health coaches after the 12-week workshop to encourage continued compliance with health plan. Referrals to community transportation services to ensure access to doctor's appointments, nutritious meals, and exercise opportunities. 	<ol style="list-style-type: none"> Utilization of the Walkability Assessment Tool. 

individualized, patient-focused stroke risk health plans, and 3) refer at risk individuals to the appropriate community resources. The community level outcomes are to: 1) establish a 12-week stroke risk reduction workshop, 2) improve nutrition by improving access to healthy foods among seniors, and 3) improve physical fitness among seniors. The policy-level outcomes are to: 1) determine environmental factors impeding access to physical activity and nutritious foods and 2) improve the utilization of public areas for walking and exercise.

Performance Measure

The Stroke Population Risk Tool (SPoRT) is a valid and reliable measure of stroke risk in this population (C-stat of 0.85 with a 0.83-0.86 95% CI for men and 0.87 with a 0.85-0.88 95% CI for women) (Manuel et al., 2015). This on-line questionnaire can be completed in-person or over the phone with a health care worker every two years or during a community-based health screening such as those used for hypertension screenings (Magnum, Kraenow, & Narducci, 2003; Manuel et al., 2015). The SPoRT uses age, sex, BMI, and self-reported health behaviors (smoking, alcohol, fruit and vegetables, leisure physical activity, stress), sociodemographic factors (country, education level), and disease and immobility factors (history of diabetes, heart disease, previous stroke, hypertension, dementia, cancer, activity limitations) to calculate a maximum score (Manuel et al., 2015). The SPoRT behavior score ranges between 0-9 for men and 0-11 for women. Each point increase in score is associated with a 12% increase in stroke risk for men and a 14% increase in stroke risk for women (Manuel et al., 2015).

As individual-level health behaviors are difficult to change, referrals to community-based programs should be well-documented and formal follow-up plans should be implemented to ensure adherence. Additional calls from a health care professional are recommended if the older adult does not use the community programs as recommended with a discussion of barriers (e.g., transportation) to program use. Community-level measures are to be collected monthly by quantifying the number of individuals participating in 12-week stroke risk reduction workshops, community-based nutrition programs, and in physical fitness classes with analyses on attrition, partial completion, and interviews with older adults in the program for quality improvement. At the policy level, measures will consist of the number of Sussex county municipalities using the Walkability Assessment Tool.

Strategy/Tactics

Individual Level

After identifying at-risk older adults, providers/health coaches/trained healthcare workers will work one-on-one with patients to encourage healthcare autonomy and foster compliance with the stroke risk reduction health plan (Savoy, Hazlett-O'Brien, & Rapacciulo, 2017). This plan will directly address the patient's SPoRT score as well as direct the patient to applicable community resources in order to encourage healthy behaviors. Greater patient buy-in will be encouraged through evidence-based practice behavioral modification strategies such as goal setting, the establishment of a social network in support of the new healthier behaviors, self-reward and positive self-talk, as well as structured problem solving to help prevent relapse into less healthy behaviors (Kahn et al., 2002). A recent study found that the most influential health education approaches are tailored to the individual patient rather than generic behavioral materials created for the general population. Not only are such individualized approaches more relevant to the patients, but they can also be tailored to their level of health literacy (Moore & Johnson, 2015).

Community Level

At the community level, individualized education and a supportive social network are enhanced through educational programs geared toward the elderly living at home. Programs are modeled after Jeon and Jeong's (2015) stroke primary prevention program which consisted of 12 consecutive weeks of stroke education on risk factors and behavioral risk reduction strategies, weekly nutrition classes, and exercise classes three times a week. The first six weeks will focus on managing stroke risk factors such as elevated BMI, hypertension, dyslipidemia, etc., thus providing a strong foundation for the second six weeks which focuses on health risk behavior reduction such as stress and obesity management. Jeon and Jeong (2015)'s stroke primary prevention program significantly reduced blood pressure, blood sugar, lipid levels, depression score, and BMI among the rural older adult participants. Following completion of this 12 week program, health care coaches will continue to follow these patients and encourage utilization of community wide nutrition and fitness programs. An important barrier for many older adults in rural areas is lack of transportation. Without access to a vehicle or public transportation older adults will be unable to participate in community programs

and are at risk for social isolation and dependence (British Columbia Ministry of Health, 2004). This will be ameliorated through referrals to organizations providing reduced rate transportation to local shopping, community centers and events, pharmacies and other medical facilities for seniors (CHEER, 2017; ITNSouthernDelaware, 2018; La Red Health Center, 2017; Lewes Senior Activity Center, 2018).

Public policy level

On a policy level, the University of Delaware's Walkability Assessment Tool, which is a three-step process engaging local stakeholders in active

Healthy and Complete Communities in Delaware: The Walkability Assessment Tool



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workshopping and auditing, will be used to aide local governments in the assessment of the strengths and weaknesses of their county's degree of walkability (O'Hanlon, Scott, & West, 2016). Walking is one of the easiest and cheapest ways for residents to become physically active. Thus, by increasing walkability through infrastructure enhancement, municipalities are not only lowering road maintenance costs, reducing traffic, and improving air quality, but they are increasing the level of fitness achieved by their residents and in turn contribute to stroke risk reduction (O'Hanlon, Scott, & West, 2016).

Possible funding opportunities

This proposed program in Sussex County could be funded with grants through the National Institutes for Health (e.g. Personalized Strategies to Manage Symptoms of Chronic Illness, Self-Management for Health in Chronic Conditions, or Population Health Interventions: Integrating Individual and Group Level Evidence), as well as through partnership with

community resources such as senior centers, Sussex County Health Coalition, and the Diabetes and Heart Disease Prevention and Control Program. Partnership with local organizations would strengthen the health plan by providing patients with a multitude of supportive and health promoting services as well as several locations and knowledgeable staff to assist with the 12 week education program.

Conclusion

High rates of stroke deaths in Sussex County, DE suggest there are unmet needs spanning the individual, community, and policy levels, particularly among rural-dwelling older adults with restricted health care access, comorbid health conditions, and poor health behaviors associated with CVAs. As a result, this health plan focuses on healthy nutrition and increased physical activity due to the growing population of obese and overweight older adults in Sussex County as well as the significant impact obesity, poor nutrition, and lack of exercise play in the development and progression of cardiovascular disease and stroke (Delaware Health Tracker, 2017; Yang et al., 2017). Ultimately the success of this health plan will be determined by the performance indicator of a deceased stroke rate among seniors in Sussex County to below the U.S. average (Delaware Health Tracker, 2017).

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DHSS Press Release

Dr. Kara Odom Walker, Secretary
Jill Fredel, Director of Communications
302-255-9047, Pager 302-357-7498
Email: jill.fredel@state.de.us

Date: October 15, 2018
DHSS-10-2018

DPH ANNOUNCES SUSTAINED FUNDING FOR OVERDOSE-REVERSING MEDICATION NALOXONE

DOVER, DE (Oct. 15, 2018) -

Increasing access to the overdose-reversing medication naloxone has been a key priority for the Delaware Department of Health and Social Services (DHSS) as state and local partners work together to develop solutions to address the opioid epidemic. In support of that, the Department's Division of Public Health (DPH) is announcing sustained funding for naloxone for first responder agencies statewide.

For the first time this year, \$100,000 in state funding was built into DPH's budget to fund the purchase of naloxone. Previously, funding for naloxone was piecemeal, using funds from DHSS's Division of Substance Abuse and Mental Health and the Department of Justice's State Law Enforcement Allocation Fund. In the absence of these funds, individual fire or police companies, or even county governments, scrambled for the resources to purchase naloxone.

To supplement the new state funds, DPH was just awarded \$538,000 per year for the next four years to purchase naloxone and support other programs for first responders. The funds come from a grant awarded by the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA).

"We continue to lose too many of our loved ones and neighbors to the addiction epidemic," said Governor John Carney. "Naloxone can give people a second chance to get medical care and be connected to resources to treat their addiction. This funding will allow more Delaware first responders to carry the medication and as a result save more lives."

Data from the Department of Safety and Homeland Security's Division of Forensic Science showed that 345 people died in Delaware last year from an overdose. So far this year, 226 people have died of suspected overdoses.

"Our goal is for every first responder to be carrying naloxone," said DPH Director Dr. Karyl Rattay, "from law enforcement, to campus security, from firefighters to ambulance crews. Previously, we were able to provide naloxone to law enforcement agencies on a limited basis. With both the state and federal funding now at our fingertips, we can greatly increase our distribution and saturation of this life-saving medication among agencies statewide."

DPH's Office of Emergency Medical Services (OEMS) coordinates the Naloxone Administration Program. Originally the program, which began in 2014, was available only to law enforcement. Currently 30 law enforcement agencies have signed agreements with, and received training through, OEMS to administer the medication as part of the voluntary program. In 2017, first responders (EMS and police) administered 2,861 doses of naloxone, compared to 2,341 in 2016.

DHSS Secretary Dr. Kara Odom Walker was present in June as Governor Carney signed legislation to expand the definition of first responders, enabling more of them - including police, firefighters, EMS personnel, lifeguards, park rangers, constables and security guards - to administer the medication to an individual whom the responder believes is undergoing an opioid-related drug overdose. Now with the expanded legislation, Wilmington Fire Department is also participating in the Naloxone Administration Program, and Secretary Walker hopes more will soon follow.

"We are so grateful for the support of our federal delegation in providing additional dollars to help us put naloxone in the hands of as many people as possible," said Secretary Walker. "Equipping more of our trained first responders with this medication to reverse the life-threatening overdose gives us another opportunity to connect that person to the resources that will help lead them to a life in recovery."

The legislation also extends liability protection for those mentioned above who administer naloxone in good faith, and maintains that liability protection for the lay person who provides emergency care in good faith as well.

Community access to naloxone has increased dramatically since 2014 when legislation was enacted making it available to the public, and in 2017 when Governor Carney signed additional legislation ensuring pharmacists had the same legal protections as doctors, peace officers and good Samaritans when dispensing the medicine without a prescription. Now many pharmacies have the medication and more friends and family members of those struggling with addiction are taking advantage of the opportunity to become trained on how to administer it in an emergency.

David Humes, of atTAcK addiction, lost his son six years ago to a heroin overdose. Humes continues to work toward increasing access to naloxone in the community. atTAcK Addiction was recently awarded a grant to do that from Highmark.

"In the aftermath of my son Greg's death I met with the investigating detective," said Humes. "His words to me were, 'If we had a 9-1-1 Good Samaritan Law or a naloxone law, your son might very well be alive today.' In the ensuing days, I made a vow to Greg that I would somehow save a life in his name. The 9-1-1 Good Samaritan Law and community access to naloxone seemed to be the vehicle to honor that vow."

Humes continued, "By expanding access to naloxone as widely as possible more lives will be saved. Thanks to the federal grant, countless lives will be saved over the next four years. atTAcK addiction is grateful to Governor Carney for including the initial funding in this year's budget, and to DPH and OEMS for their work in getting this grant. Hopefully the state will get additional federal grants to further fund community access to this life saving medication."

Within three to five minutes after administration, naloxone can counteract the life-threatening respiratory depression of an opioid-related overdose and stabilize a person's breathing, which buys time for emergency medical help to arrive. DPH recommends calling 9-1-1 immediately if you find someone in the midst of a suspected overdose, starting rescue breathing, and then administering naloxone. Naloxone is not a replacement for emergency medical care and seeking immediate help and follow-up care is still vital.

Information on community training of naloxone, along with resources regarding prevention, treatment and recovery, are available on www.HelpsHereDE.com.

First responder agencies who have questions about how to join the Naloxone Administration Program can contact the DPH Office of Emergency Medical Services at 302-233-1350.

A person who is deaf, hard-of-hearing, deaf-blind or speech-disabled can call the DPH phone number above by using TTY services. Dial 7-1-1 or [800-232-5460](tel:800-232-5460) to type your conversation to a relay operator, who reads your conversation to a hearing person at DPH. The relay operator types the hearing person's spoken words back to the TTY user. To learn more about TTY availability in Delaware, visit <http://delawarerelay.com>

Delaware Health and Social Services is committed to improving the quality of the lives of Delaware's citizens by promoting health and well-being, fostering self-sufficiency, and protecting vulnerable populations. DPH, a division of DHSS, urges Delawareans to make healthier choices with the 5-2-1 Almost None campaign: eat 5 or more fruits and vegetables each day, have no more than 2 hours of recreational screen time each day (includes TV, computer, gaming), get 1 or more hours of physical activity each day, and drink almost no sugary beverages.

Delaware Health and Social Services is committed to improving the quality of the lives of Delaware's citizens by promoting health and well-being, fostering self-sufficiency, and protecting vulnerable populations.

Screening Wilmington Communities through the Blood Pressure Ambassador Program

Dominique Medaglio, Pharm.D., M.S., Candyce Norris, B.S., Jamila Davis, B.S.

The screenshot shows the Christiana Care Health System website. At the top, there is a navigation bar with links to "Our Services", "Patient & Visitor Guide", "Health & Wellness", "About Us", and "For Health Professionals". Below the navigation bar, the Christiana Care logo is displayed, followed by links to "Careers", "Find a Doctor", "Pay My Bill", "Volunteer", "Press Room", "Contact", and "Make a Gift". A search bar with a magnifying glass icon is also present. The main content area features a large photo of a smiling woman with curly hair. To her right, the text "Center for Heart & Vascular Health" is displayed. On the left side of the main content area, there is a sidebar with a list of links under the heading "Heart & Vascular". These links include "About Our Heart & Vascular Program", "Arrhythmia Center", "Blood Pressure Ambassadors", "Events", "Photos", "Resources", "Bridges", "Cardiac Catheterization", "Cardiac Rehabilitation", "Cardiac Surgery", "Cardiology", "Cardiovascular Diagnostic Imaging", "Cardiovascular Genetic Counseling", "Clinical Trials", "Free Risk Assessment", "Heart Failure Program", "Heart Transplant Evaluation and Management", "Left Ventricular Assist Device (LVAD)", "Limb Preservation Clinic", "Patient Stories", "Pulmonary Hypertension Program", and "Structural Heart Disease Program". In the center of the main content area, there is a section titled "Blood Pressure Ambassador Program" with a sub-section titled "Get a Free Blood Pressure Check. It could Save Your Life.". This section includes a photo of a woman in a purple polo shirt taking a man's blood pressure in a park setting. Below the photo, there is a list of locations where the program is offered, including Claymont Library, Wilmington Hospital, Shoprite, and Wilmington Public Library. At the bottom of the main content area, there is a paragraph about the program's goal to reach at-risk individuals and improve cardiovascular health.

Abstract

Hypertension (HTN) is the most common chronic disease in the United States; it especially affects the African American community, with black men and women seeing higher rates of morbidity and mortality. A significant opportunity exists to improve the awareness of the dangers of HTN in these communities. Started in 2011, the Blood Pressure Ambassador Program at Christiana Care provides a unique solution, using trained volunteers to conduct blood pressure screenings throughout the Wilmington area. A peer-to-peer model is used to connect trusted individuals from the community to their friends, family, and neighbors. The Blood Pressure Ambassador Program has conducted over 12,000 screenings to date, touching residents in all 12 medically underserved areas of Wilmington. A recent analysis of the Program found that about half of all African Americans screened were found to be hypertensive and one-third did not realize that they had high blood pressure.

Introduction

Hypertension (HTN) is the most common chronic disease in the United States, affecting nearly half of all adults. It particularly is a major problem in the African American community, with black men and women having the highest age-adjusted incidences of HTN in the world (45.0% and 46.3% respectively). This leads to a 4-times greater rate of end-stage kidney disease, a 1.5-times greater rate of death from heart disease, a 2-times greater rate of fatal stroke, and a 1.3-times greater rate of non-fatal stroke when compared to Caucasians. Additionally, African Americans are 2-times more likely than Caucasians to not know they have HTN and for it to go untreated.¹ With the most recent guidelines expanding the definition of HTN (a lowered threshold from 140/90 to 130/80),² there is significant opportunity to improve the awareness of the dangers of hypertension to the public, especially within the African American community.³

The Blood Pressure Ambassador Program at Christiana Care was created in 2011 in order to improve awareness, treatment, and control of blood pressure in the African American community. Initially a small pilot project, the Program recently expanded in 2015, with a team of over 100 highly engaged community Ambassadors. As of August 1, 2018, 12,175 screenings have been conducted in Wilmington and surrounding areas. This outreach program dramatically changes the way community members access healthcare information and resources. Compared to the traditional model where people travel to clinics, the BP Ambassador Program uses a peer-to-peer model to connect trusted individuals from the community to their families, friends, and neighbors. Volunteers serve as Ambassadors to provide education, screening, and referrals to healthcare resources. The goals of the BP Ambassador Program are:

To increase the awareness of the consequences of untreated high blood pressure in the African American community, focusing on medically underserved neighborhoods in the city of Wilmington and surrounding areas.

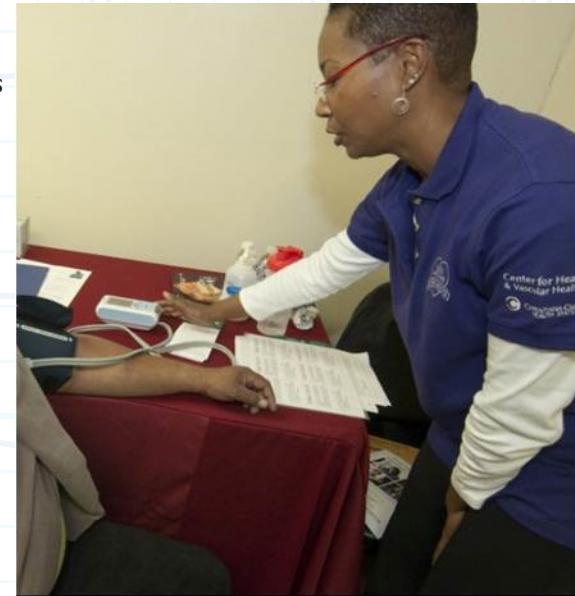
To identify African Americans with undiagnosed or inadequately treated HTN and connect them to care.

Developing a Team of Ambassadors

Ambassadors are recruited through flyers that are passed out at community events where BP screenings are taking place. Most of the volunteers have some personal

connection to hypertension (either having a diagnosis themselves or having a family member with the condition). However, the most powerful recruiting tool has been by word of mouth from other Ambassadors.

Training: People who would like to become Ambassadors are required to attend one 90-minute training class at Wilmington Hospital and are trained by the program manager. The class is designed to teach Ambassadors how to safely and effectively engage with the community and how to take a proper blood pressure measurement. Each Ambassador receives an evidence-based toolkit during the class, which consists of health



promotion resources, documentation forms, and an automatic, noninvasive BP machine. Their health promotion message includes knowing personal BP numbers, the complications of untreated hypertension, risk factors for cardiovascular disease, and how to get connected to healthcare resources. This model allows ambassadors to perform blood pressure screenings independently in their own communities. After completing initial training, the program manager sends Ambassadors monthly updates about screening opportunities at health fairs, clinics, and special events; Ambassadors can also initiate screenings on their own, including where they may worship or live.

Engagement: To keep Ambassadors engaged with the program, the program manager holds quarterly meetings for program updates, teambuilding exercises, and sharing experiences. During the teambuilding meetings, special guests are brought in to train the Ambassadors on new techniques or pertinent updates, and Ambassadors gather supplies and information to distribute in the community. Teambuilding meetings are great to keep the Ambassadors engaged but also help provide the important linkage between the organization and the community. To ensure that the program is meeting the needs of the community, the Program receives guidance from an Advisory Committee, whose

membership consists of clinicians, representatives from community organizations and the state government, and Wilmington residents.

Screening the Community

Blood Pressure Ambassadors conduct BP screenings in two ways: through scheduled events or self-initiated sessions. The BP Ambassador Program is a long-standing partner with a number of community and health-based events throughout the area, including Dance Your Heart Out, Saving Our Sisters, and Wilmington Community Day. Additionally, Ambassadors conduct BP readings on their own where they work, worship, live, and play.



Community members who agree to be screened complete a short information sheet, where demographics are collected. The Ambassador then measures the participant's BP and notes it on the sheet; a BP of 140/90 or greater is currently used as the threshold for high blood pressure. If the values are found to be over 180/110 or if the participant requests it, the BP measurement is repeated. If a participant's BP is found to be actively having a heart attack or stroke, the Ambassador would call 911 and document. The Ambassador also shares information on the importance of 'knowing your numbers', the dangers of high blood pressure, and ways to keep BP under control. All participants who have a measurement of 140/90 or greater are encouraged to follow up with a provider within 1 month. Participants with measurements over 180/110 are encouraged to immediately call their doctor or go to a medical aid unit or emergency department. Any participant without a primary care provider is given information to receive direct assistance navigating available healthcare resources.

Recent Program Impact

In 2015, the Blood Pressure Ambassador Program was enhanced to allow for more detailed data capture, including residential addresses of those who were screened. The US Department of Health and Human Services, Health Resources and Services Administration (HRSA) defines a medically underserved area as a

region where there is a shortage of personal health services for residents. The Wilmington area has 12 medically underserved census tracts that were targeted after the 2015 Program expansion; using the address data collected at screenings, the geographical reach of the Program could be mapped. Figure 1 shows the residential locations and density of program participants. This map shows that the BP Ambassador program has successfully reached community members who live in all 12 medically underserved census tracts in the Wilmington area (shaded in red).

Residential Location of Those Screened by Blood Pressure Ambassadors in Wilmington, DE

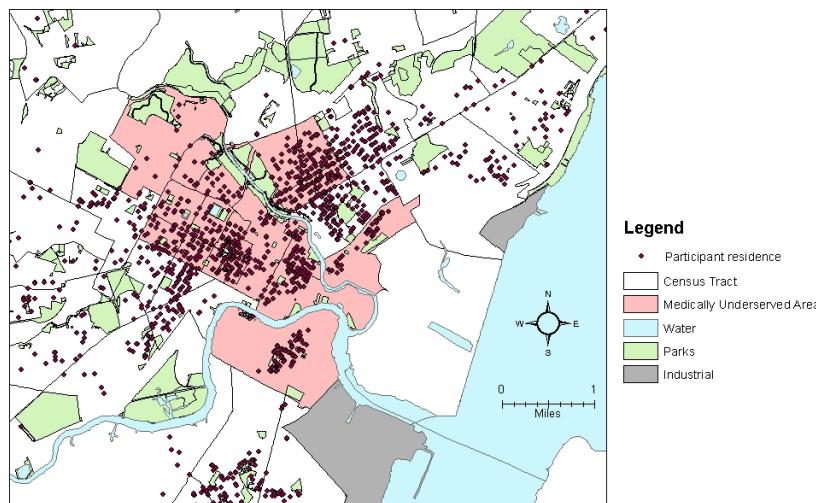


Figure 1. Residential Location of BP Ambassador Participants

Additionally, the Program's screenings have taken place at a wide variety of locations across the Wilmington area. Figure 2 shows the frequency of where screenings occurred. The most common places where Ambassadors interact with community members are at special events (i.e. health fairs, fundraisers), healthcare settings (i.e. hospitals, clinics), and places of worship.

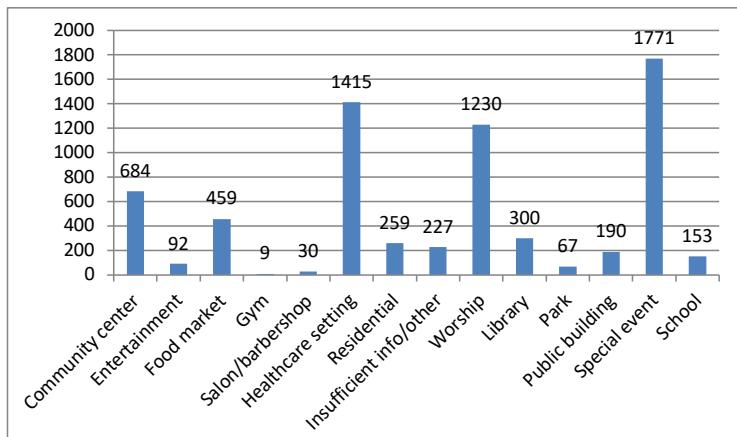


Figure 2. Locations of BP Ambassador Screenings

2017 Success Metrics

A prospective observational study was conducted January 2017 –June 2017 to analyze the program's success in reaching community members unaware of their HTN and connecting them to care. Table 1 shows the demographics of the study sample. A total of 1,018 community members were included for study; the majority of the population was female and African-American and the average age was 54.5 years.

Variable	N =1018
Age, mean (SD)	54.5 (15.7)
Female, n (%)	715 (70.6%)
Race, n (%)	
African American	651 (64.3%)
White	206 (20.3%)
Other	46 (4.5%)
Ethnicity, n (%)	
Hispanic/Latino	34 (3.4%)

Table 1. BP Ambassador Program Participants, January 2017-June 2017

As the program's mission is to target the African American population, the metrics of interest for this analysis focused on the 651 African Americans in the study population; Table 2 contains the final results. In

Table 2. Program Metrics of Success, January 2017-June 2017 African American sample

Variable	N
Measured BP is in HTN range (≥ 140/90)	320 / 651 (49.2%)
Unaware of HTN	104 / 308* (33.8%)
Total qualifying participants connected to healthcare resource navigation	26 / 28 (93.0%)

*12 persons did not respond to this survey question.

comparison to the national prevalence of HTN of 40.3% for African Americans,⁴ nearly half of the convenience sample was found to be hypertensive. Furthermore, while the national estimate of African Americans who are unaware of their HTN is 14.7%,⁵ the sample from the Program was nearly double this at 33.8%. The majority of participants (n = 623) stated they had a primary care provider and health insurance. Of the 28 community members who reported not having a primary care provider and/or health insurance, 26 (93.0%) were connected to healthcare resource navigators.

Conclusion

The Blood Pressure Ambassador Program has successfully reached Wilmington residents and has conducted over 12,000 screenings in the community, including medically underserved areas. The 2017 analysis showed that there are great opportunities to make improvements in the awareness and control of BP in Wilmington. The BP Ambassador Program is continuing to build on previous successes and lessons learned. Future work will focus on increasing African American male representation in the Ambassador Program and targeted interventions, as black males are the most affected by HTN in the US.

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This educational activity supported by the Frank M. and Robert R. Hoopes Fund held at the Delaware Community Foundation and brought to you in a partnership between the following institutions.



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Expanding care for patients infected with Hepatitis C through community partnership in Delaware

Deborah Kahal, M.D., Neal D. Goldstein, Ph.D., M.B.I., Arlene Bincsik, R.N., Tom Stephens, M.D., Karla Testa, M.D., Susan Szabo, M.D.

Abstract: Hepatitis C virus (HCV) is the most common blood-borne pathogen in the U.S., and Delaware has one of the highest sero-prevalence rates in the country. As a cause of significant morbidity and mortality, it is a public health priority to identify and link individuals with HCV to care. The demand of patients with HCV far exceeds the current availability of providers in Delaware that offer HCV management.

Objective: To propose a framework for enabling non-specialist providers within Westside Family Healthcare to manage patients with HCV.

Methods: As a recipient of a Harrington Value Institute Community Partnership grant, the HIV Community Program of Christiana Care Health System (CCHS) started working together with the NE Wilmington pilot site of Westside in July 2018 to: 1) provide HCV education to Westside, 2) implement an HCV care model at Westside, and 3) conduct programmatic evaluation of this framework's effectiveness. Our goal is to improve Westside rates of HCV knowledge amongst patients and staff, as well as to improve the HCV care continuum, starting with universal HCV screening.

Results and Conclusions: Results from the first year of collaboration will be available in August 2019. Implementation of this partnership will enable future expansion and continuation of HCV management amongst Westside sites.



Hepatitis C virus (HCV) is the most common blood-borne infection in the United States and represents a significant cause of morbidity and mortality.¹ The prevalence of chronic HCV in this country is estimated to be 1.0% of the general population, or approximately 2.7 million individuals – without accounting for high-risk, institutionalized individuals, including those who are homeless, undocumented, or incarcerated.² More recent estimates suggest that upwards of 2-4 million people in the United States have HCV³ with HCV accounting for more deaths in our country than 60 other infectious diseases combined, including human immunodeficiency virus (HIV) and tuberculosis.⁴ Despite the high national prevalence of HCV, nearly half of HCV-infected persons are unaware of their HCV status² and less than 10% of HCV-infected persons have been effectively treated and cured of HCV.⁵

In Delaware, there is an estimated statewide HCV sero-prevalence rate of 13,600 individuals, or approximately two infected persons per 100 population (95% confidence interval: 1.76-2.33 per 100 population). This prevalence is one of the highest in the country.⁶ While the Delaware Division of Public Health is actively working to increase acute and chronic HCV case reporting, there remains sub-optimal statewide HCV screening and reporting. Consequently, the reported HCV sero-prevalence rate is likely a gross underestimate of the true burden of HCV in the state. HCV is unfortunately a growing international, national and local epidemic, paralleling the striking rise in opioid-associated deaths and overdoses.⁷ Given the alarming and only increasing community burden of HCV, there is a far greater community need for HCV care than there is availability of specialists to provide this care in Delaware, New Castle County, and the city of Wilmington in particular.

At the same time, HCV treatment has revolutionized, allowing for short-courses of pan-genotypic, very well tolerated therapies (12 or, often times, 8 weeks in treatment duration) with extremely high clinical and real-world cure rates exceeding 95%.^{8,9} Moreover, Delaware Medicaid insurance restrictions on HCV treatment approval have been lifted as of 2018, allowing for patients with HCV and little to no accompanying liver damage (all the way to patients with advanced liver disease, or cirrhosis) to be approved for HCV treatment known as direct acting antiviral (DAA) therapy. HCV screening, evaluation and treatment guidelines for all patients, including patients with all HCV genotypes (1-6), cirrhotics and non-cirrhotics, compensated

and decompensated cirrhotics, and HCV treatment-experienced and treatment-naïve patients are clearly delineated in frequently updated specialty guidelines.¹⁰

In light of the growing HCV epidemic, improved HCV treatment options, expanded HCV management guidelines and access to HCV treatment, as well as limited availability of specialists to care for patients with HCV, there is an increasing demand for primary care providers (PCPs) and patients' pre-existing medical homes to provide the full range of HCV care along the HCV care continuum (Figure 1), spanning all the way from HCV screening through HCV treatment and cure. There is a growing body of evidence that appropriately trained PCPs are able to treat and cure HCV as successfully as specialists.¹¹ Additionally, the utilization of patient navigation – an intervention employed in chronic and infectious disease management to improve health outcomes by addressing patient- and systems-level barriers to care and treatment – is demonstrated to be particularly effective in improving health outcomes in high-need populations, including low-income and minority populations.¹² Regional HCV patient navigation programs, such as the "Check Hep C" program in New York City and the "C a Difference" program of Philadelphia FIGHT, serve as prime illustrations of highly successful patient navigation programs resulting in improved HCV treatment outcomes. Real-world data supports that "on-site clients" who are able to receive wrap-around, integrated HCV care within their medical home lead to improved clinical outcomes.^{11,12,13}

With support from the Harrington Value Institute Community Partnership Fund, Westside Family Health Care and Christiana Care Health System (CCHS) HIV

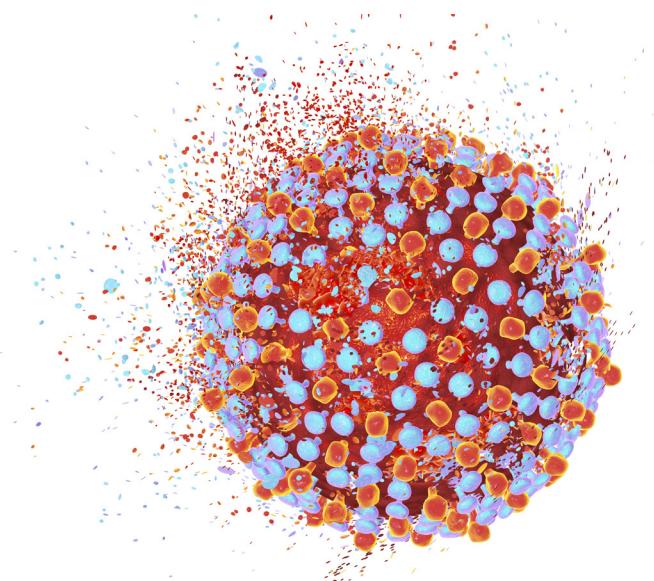
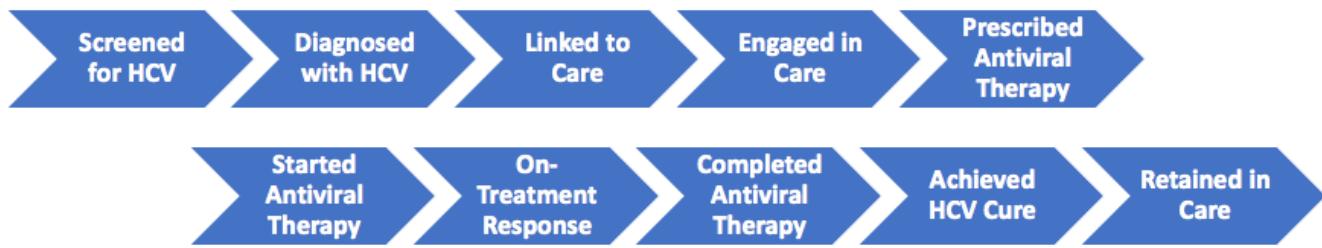


Figure 1. Hepatitis C care continuum



Community Program have undertaken a community-based collaboration to expand Westside's ability to care for patients with HCV throughout the care continuum in order to improve HCV-related health outcomes. These health outcomes extend beyond the full HCV care continuum, additionally including post-treatment follow-up and surveillance, ongoing targeted risk reduction counseling, recommended vaccinations and referral for hepatocellular carcinoma (HCC) and/or variceal screening when clinically indicated. The attainment of improved HCV health outcomes also mandates patient linkage, engagement and retention in HCV care, and ensuring that clinically complex patients, such as those patients who are HCV treatment-experienced, prior HCV treatment failures, HCV re-infections, suffering from compensated or decompensated cirrhosis or concomitant HCC, et al. are appropriately referred and linked to specialty care.



As the largest federally qualified health center in Delaware, Westside cares for approximately 31,000 patients at five sites throughout the state. This partnership will focus on the 16,000 adult patients served at Westside's two Wilmington clinical sites. The Westside Northeast clinical site, serving as the pilot site during the first year of collaboration, has an active adult patient panel of nearly 4,000 unique individuals which equates to an extremely conservative estimate of 80 adult patients with HCV. This community-based partnership will build upon pre-existing strong ties between CCHS and Westside and provide the necessary support to educate, train, and empower Westside to provide HCV care in the familiar and trusted environment of patients' pre-existing medical home. The timing of this partnership also coincides with Westside instituting on-site medication assisted therapy (MAT) for patients with opioid dependence in addition to increasing on-site services for patients with substance use disorders. This

collaborative effort represents the first concerted effort to train PCPs in Delaware to deliver HCV specialty care within patients' pre-existing primary care home.

There are three major components to this partnership: 1) education surrounding HCV infection, treatment, and management, 2) implementation of the HCV care continuum with universal HCV screening, and 3) data collection for program evaluation. The education component provided to Westside staff, including a designated HCV patient navigator, includes in-person didactic sessions, clinical preceptorships and mentoring, site-specific reference materials, as well as real-time access to Infectious Diseases specialist consultation (by providers within the CCHS HIV Community Program). The HCV patient navigator will work closely with Westside pilot site patients with HCV to ensure they are adequately linked, engaged and retained in appropriate HCV care. Concomitantly, Westside patient education includes visuals such as posters and infographics which emphasize the importance of HCV screening. Tandem with the provision of HCV education and the utilization of a designated HCV patient navigator, Westside and the HIV Community Program are working towards improving electronic medical record prompts, implementation of universal HCV screening among adult patients, and movement through the HCV care continuum.

Evaluation of this community-based partnership is ongoing and includes a mixed-methods approach of quantitative and qualitative data. We will examine changes from pre- and post-intervention focusing on rates of HCV screening and diagnosis, staging, treatment, cure and post-treatment care, as well as characterization of external HCV referrals. Along with quantitative data, Westside patients' and staff HCV knowledge will be tracked with regular administration of a validated HCV questionnaire.¹⁴ Administration of qualitative interviews of Westside providers will provide a richer understanding of how this partnership affects providers' subjective experiences and feelings surrounding the provision of HCV care.

This partnership aims to improve rates of HCV knowledge amongst Westside patients and providers as well as improve the HCV care continuum, starting with universal HCV screening. The engagement of a HCV patient navigator to aid in educational efforts and help patients with HCV to navigate their HCV care will further bolster our goal of improving HCV knowledge and linkage to and through care. As Westside PCPs are able to provide highly-competent HCV evaluation, care, treatment and post-treatment follow-up, we expect this program to not only succeed in decreasing the community burden of HCV and strengthening Westside and CCHS's existing relationship, but also to increase the capacity of the HIV Community Program to provide HCV specialty care, thereby improving the overall health of the populations served by these healthcare providers.

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Dr. Kahal is an HIV Program physician at Christian Care Health System. Dr. Kahal has conducted HIV/AIDS research, co-authored an article published in AIDS and Behavior and presented lectures, teaching sessions and grand rounds at HUP, University of Pennsylvania Perelman School of Medicine, FACES (Family AIDS Care & Education Services) UW Medical Center Psychiatry Conference in Nairobi, Kenya, and Tulane School of Medicine.



Neal D. Goldstein, Ph.D., M.B.I. is an infectious disease epidemiologist at Christiana Care Health System (Newark, DE), and holds an appointment as assistant research professor in the Department of Epidemiology & Biostatistics at Drexel University Dornsife School of Public Health (Philadelphia, PA). His research spans several disciplines including vaccine-preventable diseases, sexual minority health, pediatric infectious diseases, and women's health surrounding pregnancy. He also possesses a background in biomedical informatics with detailed knowledge of hardware and software in the healthcare domain. Most recently, he has focused on translational epidemiology, or moving from knowledge generation to application and advocacy. He writes a science blog, which is available at www.goldsteinepi.com/blog.



Arlene Bincsik is a registered nurse and the director of the HIV program at Christiana Care. She was the recipient of the Sister Dolores Macklin Red Ribbon Guardian Angel Award from the Delaware HIV Consortium for her efforts to improve the overall health of individuals with HIV/AIDS and empower them to live richer and healthier lives.



Dr. Testa currently practices primary care at Westside Family Healthcare in Wilmington, DE, a Federally Qualified Health Center. She finds this to be an excellent bridge to combine her interests in global health and public health locally. Dr. Testa continues to be a leader in the global health. She hopes to continue to work with residents and their community outreach and advocacy projects as well.



Susan Szabo, M.D. is the Medical Director of the HIV Program at Christiana Care Health System. Since 1993, she has been responsible for coordinating and overseeing the care of patients with HIV infection.



Dr. Stephens works at Westside Family Healthcare and specializes in Family Medicine.

COMMUNITY ENGAGED RESEARCH LEXICON

OF TERMS

Allostatic Load

The wear and tear on the body that accumulates as an individual is exposed to repeated or chronic stress.

Cirrhosis

A chronic disease of the liver marked by degeneration of cells, inflammation, and fibrous thickening of tissue.

Community Advisory Panel

An advisory panel or board, consisting of representatives of the general public, who meet with representatives of the study or institution to relay information between groups.

Community Health Worker

Members of a community chosen by community members or organizations to provide basic health and medical care to their community. This includes preventive, promotional, and rehabilitative care. CHWs bridge cultural and linguistic barriers, expand access to coverage and care, and improve health outcomes for their communities.

Comorbidity

The simultaneous presence of two or more chronic diseases or conditions in a patient.

Compensated Cirrhosis

The liver is scarred, but still able to perform most of its basic functions at some level.

Decompensated Cirrhosis

Liver damage and scarring has progressed to the point where the liver can no longer function properly, the patient begins to experience more severe symptoms of liver disease, and the risk of severe complications will increase.

Demographics

Statistical data relating to the population and groups within populations. These data can include age, income, education, etc.

Disparity

Differences or imbalances. Lack of equality.

Empirical

Based on or verified by observation or experience, rather than theory or logic.

Evidence Based Practice (EBP)

The integration of clinical expertise, patient values, and the best research evidence into the decision making process for patient care.

Focus Group

A demographically diverse group of people assembled to participate in a guided discussion about a particular subject.

Generalizability

In study design, this is the ability of a study's findings and conclusions based on its sample population to be extended to the population at large.

Genotype

The genetic constitution of an individual organism.

Grey Literature

Materials and research produced by organizations outside of the traditional commercial or academic publishing and distribution channels. Common publication types include reports, working papers, government documents, white papers, and evaluations.

Hyperlipidemia

Also known as high cholesterol. Abnormally high concentration of fats or lipids in the blood.

Hypertension

Also known as high blood pressure. Blood pressure readings of over 140/90 are considered high.

Intervention

An action or study undertaken to attempt to improve a medical situation.

Likert Scale

A type of rating scale used to measure attitudes or opinions. With this scale, respondents are asked to rate items on a level of agreement. Most usually strongly agree, agree, neutral, disagree, and strongly disagree are used, but variations can be used based on frequency (always, sometimes, never), quality (very good to very bad), likelihood (definitely to never), and importance (very important to unimportant).

Medical Home

A team-based health care delivery model which provides comprehensive primary care. A lead health care provider or practice-based care team provides comprehensive and continuous medical care to patients to maximize health outcomes and facilitate partnerships between patients, clinicians, medical staff, and families.

Mixed Methods Research

A methodology for conducting research that involves collecting, analyzing and integrating quantitative and qualitative research.

Morbidity

The condition of being diseased, the rate of disease in a population.

Mortality

Death, especially on a large scale.

Multimodal

Using many methods.

Needs Assessment

A process used by organizations to determine priorities, make improvements, or allocate resources. It determines the gaps between the current state and the wanted condition.

Pan-Genotypic

A drug that treats numerous genotypes.

Pathophysiology

The disordered physiological processes associated with disease or injury.

Patient Navigator

An individual who guides patients with suspicious findings or a given diagnosis through and around common barriers in the health system to help ensure timely diagnosis and/or treatment.

Peer-to-Peer Model

A research approach wherein members of the research target group adopt the role of active researchers, interviewing their peer group about experiences relating to the research topic.

Pilot Program

Also known as: feasibility study, experimental trial. A small-scale, short-term experimental project or program that helps determine how a large-scale project or program might work in practice.

Prevalence

The proportion of a population found to be affected with a particular disease or medical condition at a given time.

Quality of Life (QOL)

The general well-being of individuals and societies, outlining negative and positive features of life. QOL includes physical health, family, education, employment, wealth, safety, security, freedom, religious beliefs, and the environment.

Qualitative Research

A scientific method of observation to gather non-numerical data. This type of research often looks at concepts, characteristics, and descriptions, and is often used in the social and natural sciences disciplines. It may include things like personal interviews or focus groups.

Quantitative Research

A systematic, empirical investigation of observable phenomena via statistical, mathematical, or computational techniques. It may include experiments, randomized control trials, surveys, observational studies, etc.

Recidivism

The tendency of a convicted criminal to reoffend.

Sampling

The act of selecting a suitable representation of a population. Because studies cannot effectively study the entire population, a small sample must be gathered instead. To be an effective sample, the sample population must be representative of the population in question. Different types of sampling include snowball sampling (existing study subjects recruit future subjects from among their acquaintances), random sampling (members are selected by chance), convenience sampling (a study recruits subjects based on convenience (i.e. all the students in a class)), etc.

Sero Prevalence

The level of a pathogen (bacteria or virus) in a population, as measured in the blood.

Socioeconomic Status (SES)

An economic and sociological combined total measure of a person's work experience and of an individual's or family's economic and social position relative to others, based on income, education, and occupation.

Social Determinants of Health

Biological, socioeconomic, psychosocial, behavioral, and/or social factors that contribute to a person's current state of health. These include biology, genetics, individual behaviors, social environment, physical environment, access to health services and quality health care.

Social Ecological Framework

A theory-based model that considers the interplay between individual, relationship, community, and societal factors, and how these determine behavior.

Theme

In research, especially qualitative research, a theme is an idea, subject, or topic of discourse that arises amongst many study participants as important to the topic at hand.

Translational Research

An approach to research that emphasizes partnership between researchers and communities, and seeks to include the voice of those who are likely to be impacted by this research. New knowledge or research is used to create new approaches for prevention, diagnosis, and treatment of disease.

Validation

Proving the accuracy of something, to confirm. In research, a survey instrument or measurement device must be validated (proved to be accurate).

COMMUNITY ENGAGED RESEARCH RESOURCES

The Delaware Academy of Medicine/Delaware Public Health Association strives to be engaged in and relevant to our Delaware community. Our mission is to enhance the well-being of our population, and we work with Delaware Hospitals, Universities, and other non-profits to bring you the most recent, up to date health knowledge available. But you know things about your communities that we do not. You know the problems, challenges, and issues that are facing your neighborhoods and families.

The topic of this month's Journal is Community Engaged Research (CER). This type of research allows individuals, communities, and groups to engage with more "traditional" research institutions and implement the programs that their communities need. So speak up! Below you will find several resources in Delaware dealing with CER, but they are not the only ones. Go out into your communities and find the groups, find the people doing the work, and join them. If you have any questions, or would like contact information for the groups or projects listed in this edition of the journal, drop us a line.

CER doesn't work without the community. Only by working together can we make Delaware healthier and happier than it has ever been!

ACCEL Community Engaged Research

<https://www.de-ctr.org/ace-award> | Create and expand Community-Academic Research Partnerships by developing a cadre of independent Community Engagement Scholars in Delaware trained to conduct research that engages the community.

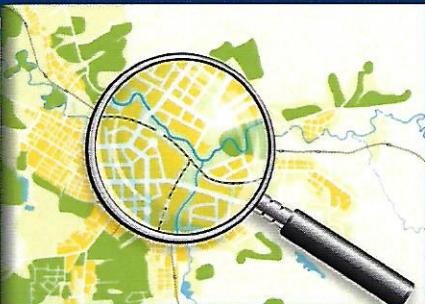
Patient Centered Outcomes Research Institute (PCORI)

<http://www.pcori.org/> | Established to fund research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information.

University of Delaware: Partnership for Healthy Communities

<https://sites.udel.edu/healthycommunities/> | Seeks to improve the health and well-being of Delaware residents, especially those living in communities that experience social and economic disadvantages. A partnership with community-based organizations, state and local agencies, students, and University of Delaware researchers.

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Delaware Journal of Public Health

Submission Guidelines
updated October 16, 2018

About the Journal

Established in 2015, **The Delaware Journal of Public Health** is a bi-monthly, peer-reviewed electronic publication, created by the Delaware Academy of Medicine/Delaware Public Health Association. The publication acts as a repository of news for the medical, dental, and public health communities, and is comprised of upcoming event announcements, past conference synopses, local resources, peer-reviewed content ranging from manuscripts and research papers to opinion editorials and personal interest pieces, relating to the public health sector. Each issue is largely devoted to an overarching theme or current issue in public health.

The content in the Journal is informed by the interest of our readers and contributors. If you have an event coming up, would like to contribute an Op-Ed, would like to share a job posting, or have a topic in public health you would like to see covered in an upcoming issue, please let us know.

If you are interested in submitting an article to the Delaware Journal of Public Health, or have any additional inquiries regarding the publication, please contact *DJPH* Deputy Editor Elizabeth Healy at ehealy@delamed.org, or the Executive Director of **The Delaware Academy of Medicine and Delaware Public Health Association**, Timothy Gibbs, at tgibbs@delamed.org.

Information for Authors

Submission Requirements

The DJPH accepts a wide variety of submission formats including brief essays, opinion editorials pieces, research articles and findings, analytic essays, news pieces, historical pieces, images, advertisements pertaining to relevant, upcoming public health events, and presentation reviews. If there is an additional type of submission not previously mentioned that you would like to submit, please contact a staff member.

Submissions should be completed under general APA guidelines for formatting and citations. Articles should be written in Microsoft Word format, in a clear, easily readable font with 1.5-inch to 2-inch spacing, and 1-inch margins. The suggested font is 12 point Times New Roman. Once completed, articles should be submitted via email to ehealy@delamed.org as an attachment. Graphics, images, info-graphics, tables, and charts, are welcome and encouraged to be included in articles. Please ensure that all pieces are in their final format, and all edits and track changes have been implemented prior to submission.

Submission Length

While there is no prescribed word length, full articles will generally be in the 2500-4000-word range, and editorials or brief reports will be in the 1500-2500-word range. If you have any questions regarding the length of a submission, or APA guidelines, please contact a staff member.

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Conflicts of Interest

Any conflicts of interest, including political, financial, personal, or academic conflicts, must be declared prior to the submission of the article, or in conjunction with a submission. Conflicts of interest are any competing interests that may leave readers feeling misled or

deceived, and/or alter their perception of subject matter. Declared conflicts of interest may be published alongside articles in the final electronic publication.

Nondiscriminatory Language

Use of nondiscriminatory language is required in all DJPH submissions. The DJPH reserves the right to reject any submission found to be using sexist, racist, or heterosexist language, as well as unethical or defamatory statements.

Additional Documents and Information for Authors

Please Note: All authors and contributors are asked to submit a brief personal biography (*3 sentences maximum*) and a headshot along submissions. These will be published alongside final submissions in the final electronic publication. For pieces with multiple authors, these additional documents are requested for all contributors.

Abstracts

Authors must submit a structured or unstructured abstract along with their article.

The word limit is **200 words**, including headings. A title page should be submitted with this abstract as well.

Structured abstracts should employ 4-5 headings:

Objectives (begins with “To...”)

Methods

Results

Conclusions

A fifth heading, Policy Implications, may be used if relevant to the article.

Trial Registration information is required for clinical trials and must be included in the final version abstract

All abstracts should provide the dates(s) and location(s) of the study if applicable.

Note: There is no Background heading.

Example of Information in Abstract

Objective: State the objective or study question starting with “To ...” (e.g., “To determine whether...”).

Methods: Provide the basic design, place, year(s), setting, and number of participants of the study. If applicable, include the name of the study, the duration of follow-up. Indicate exposure and outcomes.

Results: Include quantitative results.

Conclusions: Provide only conclusions of the study that are directly supported by the results, whether positive or negative.

Policy implications: Provide a statement of relevance indicating implications for health policy, avoiding speculation and overgeneralization.

Trial Registration: For clinical trials, the name of the trial registry, registration number, and URL of the registry must be included in the cover letter ONLY and in the manuscript only after it is officially accepted.

Relevant Abbreviations should be mentioned here and will not be counted in the word limit.

Index of Advertisers

Save The Date For Our Policy Academy	7
University of Delaware	
Lung Cancer Screening	13
Division of Public Health	
The DPH Bulletin October 2018	22
Division of Public Health, Department of Health and Social Services	
The DPH Bulletin November 2018.....	23
Division of Public Health, Department of Health and Social Services	
The Nation's Health - October 2018.....	31
American Public Health Association	
The Nation's Health - November 2018	37
American Public Health Association	
2018 Health Summit: Communicable Diseases	61
Medical Society of Delaware	
DHSS Press Release	68
Delaware Division of Public Health	
Medical - Dental Lecture 2019	74
Frank M. and Robert R. Hoopes Fund	
JeffX Global Health Conference	75
Philadelphia University and Thomas Jefferson University	
Advancing the Science to Improve Population Health	83
National Academy of Medicine	
DJPH Submission Information	84
Delaware Journal of Public Health	

Notes:



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The Delaware Academy of Medicine is a private, nonprofit organization founded in 1930. Our mission is to enhance the well being of our community through medical education and the promotion of public health. Our educational initiatives span the spectrum from consumer health education to continuing medical education conferences and symposia.

The Delaware Public Health Association was officially reborn at the 141st Annual Meeting of the American Public Health Association (AHPA) held in Boston, MA in November, 2013. At this meeting, affiliation of the DPHA was transferred to the Delaware Academy of Medicine officially on November 5, 2013 by action of the APHA Governing Council. The Delaware Academy of Medicine, who's mission statement is "to promote the well-being of our community through education and the promotion of public health," is honored to take on this responsibility in the First State.