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| Complex Chronic Disease Taskforce: Final Report June 2016 |  | Chair: Senator Margaret Rose Henry  Co-Chair: Representative Stephanie T. Bolden  Legislative Sponsor: Senator Bethany Hall-Long |
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# Overview

The Complex Chronic Disease Task Force was established to examine complex chronic disease management in Delaware and make recommendations for the improvement of services and access to high quality care. Between November 2015 and May 2016, the Complex Chronic Disease Taskforce met to discuss these issues. For the purposes of this report, a “complex chronic disease” is defined as a condition, involving multiple co-occurring diseases, which requires the attention of multiple health care providers or facilities and possibly community or home-based care[[1]](#footnote-1).

The Taskforce, established by SCR 34[[2]](#footnote-2), was charged with making recommendations for the improvement of services and access to high quality care for individuals with complex chronic diseases. The taskforce was comprised of 13 members[[3]](#footnote-3). Rather than focus on a few select complex chronic diseases the Taskforce chose to examine the crosscutting, systemic concerns facing those with any complex chronic disease. The group narrowed the systemic concerns to: 1. holistic, coordinated healthcare efforts, 2. reimbursement, 3. self-management, 4. focus on the caregiver, and 5. transition from pediatric care to adult care. The final section of the report outlines eight actionable recommendations, including coordination models, and legislative agenda items.

# Holistic, Coordinated Healthcare Efforts

Holistic Care has been defined as: “a system of comprehensive or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the person; his or her response to illness; and the effect of the illness on the ability to meet self-care needs.”[[4]](#footnote-4) Health care is beginning to move toward a comprehensive, coordinated care model. In the most explicit way, this new paradigm is showing up in new insurance plan payment models with value-based reimbursement. For example, Medicaid has moved from primarily a fee-for-service model to an integrated managed care delivery system organized to manage cost, utilization and quality. In other words, the Managed Care Organizations are contracted to accept a set per member per month capitation payment, instead of reimbursement each time the client seeks services. In theory this would incentivize the provider to give the client the services and tools in a “one-stop-shop,” but this does not eliminate those individuals who are going to use other provider, medical aid or emergency room services regardless of how much the primary care provider expands services or hours to meet their needs. This payment model concern is further discussed in the “reimbursement” section of the report.

In that way, this systemic component crosscuts all the others. Specifically, holistic care means looking at the patient/client as a whole person, versus segmenting or siloing an individual’s various diseases, disorders, or other health concerns. Furthermore, coordinating care means that all those involved in that client’s healthcare, whether it be the primary care provider, specialist, caregiver, etc., all work together as a team to meet the client’s quality of life goals. One of the more creative ways in doing this is to create a client-directed, holistic approach to better coordinate care, while placing more responsibility for communication and coordination on the providers, rather than the client and caregiver.

TECHNOLOGY

To accomplish this, a new infrastructure or incorporation of more advance technologies and tools would need to be used throughout the state. Hospitals and medical practices with a larger infrastructure are currently utilizing technology well, but these systems often leave out smaller medical practices, which limits the ability for specialists to collaborate. For example, Christiana Care’s Care Link program has a robust technology enabled network of care coordinator support services, but this system is not open to providers outside of the Christiana Care program.

The coordination of care becomes especially important during times of transition between providers. The challenges specific to the transition from pediatric to adult care is discussed further later in this report. However, regardless of the type of care, use of the Delaware Health Information Network (DHIN) by all providers may improve coordination of care. DHIN is an electronic health data system tool that facilitates and supports the needs of consumers, health plans, policy makers, and providers to share real time data and improve the quality of health care. In practice, the primary care provider can obtain lab results for the laboratory electronically, and then place the results with the patient’s full medical file at the primary care office. However, the DHIN does not provide access to all independent midlevel providers such as registered dieticians or NEED OTHER EXAMPLE OR TWO providers. If the DHIN can expand to include all interested providers, then the holistic communication and timely care coordination in Delaware would be expanded.

Continually, enhancing Delaware’s healthcare communication platforms through the use of telemedicine can be beneficial for accessing specialty care or to ease the transportation burden on patients. However, the reimbursement model needs to account for and/or incentivize the time the specialist and the provider utilize the telemedicine technology. The Medicaid Managed Care Organizations are currently using telemedicine, but it remains an underutilized tool that has the capacity to directly impact many of the other systemic concerns outlined later in the report. Telemedicine can also be used to expand already-established managed care programs, as well as aide in effecting a seamless transition from pediatric to adult care.

CLIENT-DIRECTED, HOLISTIC CARE

In terms of holistic care, more attention needs to be given to including mental, physical, and spiritual health services within all treatment plans. Specifically, mental health issues such as depression can negatively impact physical chronic diseases. However, less attention may be given to the management of the psychological issues. Those mental health conditions can then lead to more physical pain, perpetuating the need for pain prescriptions. Regardless of the source of the physical pain, individuals living with complex chronic diseases are likely to experience some kind of physical pain and may be prescribed medication to help alleviate it. Providers and public health and safety officials alike are aware that an increased reliance on prescriptions to manage chronic pain can lead to addiction. Therefore, it is extremely important that all the doctors and specialists involved in a patient’s care communicate and pay special attention to the management of pain, while monitoring prescription use.

In 2010, in light of these concerns, the Department of Public Safety and Homeland Security proposed legislation to create the Delaware Prescription Monitoring Program (PMP)[[5]](#footnote-5). The PMP is a system that collects information on all controlled substances. The system allows prescribing physicians to obtain immediate access to an online report of a patient’s currently prescribed controlled substances. The Prescription Action Committee (PDAC), a public-private partnership started by the Division of Public Health and the Medical Society of Delaware to enable multiple stakeholders to work collaboratively to address the prescription drug abuse problem in Delaware. In 2013, the PDAC published a report and recommendations related to Delaware’s accelerating drug overdose mortality rate. In the report, the committee made recommendations[[6]](#footnote-6) which included expanding PMP legislation to require practitioners with controlled substance licenses to register for access to the Prescription Monitoring Program (PMP). The Prescription Action Committee also recommended that the PMP be linked to the DHIN.

When thinking about holistic care, more attention needs to be paid to the caregiver(s) and their ability to maintain their own physical and mental health while providing ongoing care for their loved one. This is discussed in a later section of the report, but whenever possible the primary care physicians should include a check-in with the caregiver as a part of the comprehensive care plan and services for the patient.

The **P**rograms of **A**ll-Inclusive **C**are for the **E**lderly (PACE) model delivers all needed medical and supportive services, on the entire continuum of care and services, to adults with chronic care needs, while maintaining their independence in their home for as long as possible. The caveat to this model is that clients must be certified by Delaware that they need nursing-home level care, and then the patient must turn over their entire medical services to the program. This means they would not be able to keep their own primary care provider.

Delaware’s Long-Term Care Medicaid has a statewide PACE model, which currently serves about 180 elderly, clients who are certified as requiring “nursing-home level” care[[7]](#footnote-7). The Program is operating through Saint Francis Healthcare in Wilmington. The population served by PACE thus far has not expanded outside the city limits. The Taskforce recommends expanding the model to all elderly who qualify through their level-of-care needs. This would require collaboration between and among all insurance providers in the state, as well as other healthcare providers to ensure clients in Kent and Sussex Counties are also being reached. There may also be an opportunity to expand to adults with nursing home level of care needs. In any case there would need to be an expansion of capacity in community services.

Restructuring the PACE model to include other age groups who have complex chronic diseases, or at least expanding the program to encompass all elderly individuals who qualify, may be a promising way to accomplish the goals of holistic and coordinated care.

Finally, joining the 12 other states[[8]](#footnote-8) that have implemented a statewide All Payer’s Claims Database[[9]](#footnote-9) (APCD) will allow Delaware to most effectively compile and interpret health-related data for all Delawareans. Currently, Delaware can only access certain insurance companies data, namely that of Medicaid and Medicare, which does not provide a full picture of the current state of Delaware’s healthcare services. The APCD would allow the state to pull data across all insurance types, in order to evaluate the current service mix and in turn, make better decisions with regards to resource allocation. In 2012, a group of stakeholders, including Delaware’s Department of Health and Social Services, Division of Public Health, the Health Care Commission, insurers, and hospitals, drafted legislation[[10]](#footnote-10) to establish an APCD in the state, but the bill was never introduced. Working with stakeholders to work through any points of contention to get the bill introduce and passed would allow for a more streamlined data sharing and data analysis.

Throughout this discussion it is important to remember State Innovation Model (SIM) grant and its respective priorities and plans. All efforts to improve holistic and coordinated care should be coordinated with the SIM and the Delaware Center for Health Innovation (DCHI). The SIM grant is already working to engage the multiple stakeholders, transform the payment model to link to health outcomes, share resources and services in order to support providers, and encourage the use of a flexible workforce and health information technology to improve care. Thus, many of the challenges discussed in this report are also being addressed by the SIM. For example, the SIM is already working to increase access to clinical data, define opportunities to standardize approaches to care, and support the Healthy Neighborhoods Program[[11]](#footnote-11).

# Reimbursement

Insurance reimbursement policies and practices regardless of insurance provider may be one of the biggest and most explicit barriers to access care. It can be extremely stressful and confusing for individuals and families to choose the optimal insurance provider and/or insurance plan, especially if forced to choose between one service and another. There are a variety of different agencies, departments, and companies involved in deciding what services are reimbursable. Clients and loved ones may need help to cut through red tape to get the care they need.

Specifically, all insurance providers should focus on including coverage for primary prevention and care coordination. In order to do this, the state should work with insurance companies, as well as the Insurance Commissioner, to restructure the payment model to a payment or reimbursement for care coordination. Private insurers and Medicaid Managed Care Organizations are already transitioning to this new “pay for value” or “pay for total cost of care” model. Beginning in 2015, Medicare established a payment model for non-face-to-face care coordination services for Medicare beneficiaries with multiple chronic conditions. Under this model, Medicare pays separately under the Medicare Physician Fee Schedule, to cover calls between patients and providers to review care, such as linking patients to specialty care or health promotion[[12]](#footnote-12). This payment model should be adopted by all insurance companies to ensure that all beneficiaries are able to access care coordination through technological means, such as telemedicine. Primary care providers should be able to coordinate between specialists, without having to worry about unreimbursed time.

Despite the already evolving payment and reimbursement methods, providers are still concerned that they will be penalized for those patients who continually use acute care facilities (i.e. - emergency room) instead of utilizing their primary care physicians. Providers are concerned that the current reimbursement model does not have a safeguard to protect providers from being penalized for those individuals. However, there alternative value-based payment models that may be less risky for providers.

The Taskforce sees the benefits of including community health workers, primary prevention programs, and self-management programs within the insurance reimbursement structure. Community health workers have a proven record of improved, positive healthcare outcomes[[13]](#footnote-13). Minnesota has an effective community health worker program, which includes a mechanism for certified community health worker reimbursement[[14]](#footnote-14). In the Minnesota program, a community health worker (CHW) collaborates with Minnesota’s Managed Health Care Program (MHCP) recipients who may have difficulty understanding providers due to cultural or language barriers. CHWs extend the reach of providers into underserved communities, reducing health disparities, enhancing provider communication, and improving health outcomes and overall quality measures. Working in conjunction with primary care providers, CHWs can bridge gaps in communication and instill lasting health knowledge. These providers must have a valid certificate from the Minnesota State Colleges and Universities (MnSCU) demonstrating that the applicant has completed an approved community health worker curriculum. The CHWs are reimbursed $20/ half hour visit, and help facilitate the state’s self-management education programs.

# Self- Management

According to Center for Disease Control (CDC), “self-management” means providing health education resources and tools to patients, in order to improve their health outcomes[[15]](#footnote-15). However, self-management goes far beyond merely providing patients and caregivers with information, rather it empowers patients to take an active role in their care[[16]](#footnote-16). Self-management gives patients ownership over the management of their chronic disease, and empowers them to make impactful changes in their lifestyles, and thus, their health. It consistently reminds and redirects all health care to be patient-centered, especially when considering healthcare goals. Self-management programs are credible, low-cost, and often more convenient than a typical doctor’s or hospital visit[[17]](#footnote-17).

One of the best known and most highly regarded self-management programs for people with chronic conditions is Stanford’s Chronic Disease Self-Management Program (CDSMP). This program is a low-cost program that helps adults with chronic conditions learn how to manage and improve their health. Interactive workshop sessions focus on problems that are common to individuals dealing with any chronic condition. Topics include pain management, nutrition, exercise, medication use, emotions, and communicating with doctors. The program has demonstrated the potential for significant cost savings including:

* $714 per person savings in emergency room visits and hospital utilization.
* $364 per person net savings after considering program costs of $350 per participant.
* Potential savings of $6.6 billion by reaching 10% of Americans with one or more chronic conditions[[18]](#footnote-18).

Delaware Division of Public Health (DPH) uses two established self- management program curriculums. There is a curriculum for Chronic Disease, as well as Diabetes. Each is a 6-week course, and each weekly class lasts about 2.5 hours. The curriculum focuses on healthy lifestyle (nutrition, exercise), medicine adherence, etc. The Diabetes Self-Management Program is run through funding from a Center for Disease Control and Prevention (CDC) grant, Delaware Division of Services for Aging and Adults with Disabilities (DSAAPD), as well as the Health Fund (National Tobacco Settlement Funds). It was first implemented over five years ago and 3,000 people have gone through this program. The Chronic Disease Self-Management program is a more recent program and is run through fund from DSAAPD. Neither of these programs is currently reimbursable through Medicaid.

Each group program also employs a train-the-trainer model. This model allows community-based providers to have staff trained on how to facilitate the program and thus expands their reach to more clients. This differs from the self-management programs in other states, which may only uses certified community-health educators. It is important to note that the community-health educators differ from the previously-mentioned community-health workers (CHW). CHW serve in many capacities, but are not the ones who facilitate self-management programs. The community-health educators are those individuals who have been trained to facilitate the self-management programs, but do not make home-visits and help with the coordination of care.

While the Division of Public Health (Stanford) programs do not use certified community-health educators, they still hold an important place in the larger care structure. These programs can provide the basic self-management information, while partnering with the healthcare specialists for needed expertise. They are not meant to replace the physician or one-to-one education that is offered by specialists.

While these programs are beneficial, the state should also work to create a more streamlined promotion, incentive, and reimbursable path to individual self-management care sessions prior to diagnosis. With many chronic diseases, such as diabetes, proper nutrition, medication use and exercise are key factors to ensuring quality of life and effectively managing the disease. While self-management care programs, like the ones the Delaware Division Public Health facilitates do cover these topics components, it cannot and should not replace individualized direct services through registered dieticians and licensed nutritionists dieticians just as it does not replace medical or nursing care. The self-management programs are taught in a group setting and use lay leaders. The programs are entirely different than the services and education the individual practitioners provide. Referrals to the self-management programs are done through the client’s medical provider, and thus, a referral to a specialist, such as a dietician should also come from the provider.

In order to better promote both the group self-management programs and the individual educator sessions, the state should better promote and expand the capacity with the use of technology, including online classes, webinars and telemedicine. The Stanford model does already provide an online workshop for Diabetes Self-Management; however, this has not been widely advertised and may be underutilized in the state.

# Focus on the Caregiver

One of the unique facets in complex chronic disease management and care is that often more than just the diagnosed client is significantly affected. Caregivers for the client, whether that means a parent, spouse, or other family member or friend, are often overlooked because the only reimbursable services for the provider are those given to the patient. Providers should look at ways to better support the caregivers through support groups, state or community agencies and/or by partnering with a community healthcare worker, who can be charged with establishing health care check-ins with the caregiver. The check-ins might include:

* caregiver’s health and wellness needs
* community resources
* respite services
* employment issues such as balancing maintaining employment and providing care

Long Term Care (LTC) Medicaid has a model for Self-Directed Services, which enables the client to designate a caregiver as their provider. The caregiver can enlist as a caregiver with a participating provider and be reimbursed through that provider. Thus, the participant or their designated caregiver have decision making authority over certain services and take direct responsibility to manage their services with the assistance of available supports. Participants or their caregiver are afforded the decision-making authority to recruit, hire, train, and supervise the individuals who furnish their services. There is also a respite service run through Medicaid’s Long Term Care, which provides care to members unable to care for themselves due to the need for relief for the member’s caregiver. Through DHSS, Division of Services for Aging Adults and Persons with Disabilities (DSAAPD) already has a model for paying the caregiver. The reimbursement model for this DSAAPD services is through the Attendant Care Services program, which is similar to the Medicaid LTC model, in that the caregiver is reimbursed thru a designated provider, not directly.

# Transition from Pediatric Care to Adult Care

This transition requires a specific and unique structured program to ensure that care and/or management is not interrupted. Transitional Care models provide the core elements to reduce fragmentation or interruption in care that may occur between the pediatric to adult healthcare services. Vulnerable transitional populations may include those with Cystic Fibrosis, Diabetes, Hemophilia, Juvenile Rheumatoid Arthritis, Sickle Cell Disease, In order to best address this transition a model approach needs to be created. One potential model is the Six Core Elements of a Structured Program. The elements included in this program provide a foundation for a holistic, comprehensive plan to prepare the patient, caregiver, and healthcare provider(s) for the transition. The six core elements include:

* 1. Transition Coordinator or Case Manager
  2. Collaborative effort between pediatric and adult specialists
  3. Time
     1. A minimum of 6 months
     2. In order to foster and strengthen the patient’s independence, begin the transition conversation at a younger age.
  4. Provide Educational Resources
     1. Provide a chronic disease sub-specialty binder with link to website or app
  5. Offer Group Education/Support Classes
     1. For both the parent/caregiver and the patient
  6. Track Outcomes
     1. Follow the patient for at least 1 year to evaluate the process and measure the outcomes

The state should work to establish a tracking system to better understand unmet needs, co-morbidities, diagnoses, mortality rates, and caregiver outcomes in the 1 to 10 year after the transition to adulthood.

9

In Philadelphia there is a model transition program, called the Young Adult Transition Team (YATT), which integrates an adult primary care provider and community-based organizations in the care of youth with a chronic medical condition in the years leading up to transition. The YATT program was run through a partnership with the Sickle Cell Disease Association. This program was grant funded, so a more sustainable funding structure would need to be established, and the time the adult physician contributes to the care of the youth while still a minor, should be reimbursable.

# Recommendations

1. Open the Delaware Health Information Network to include all interested specialists and providers. These specialist/providers may include dieticians, smaller practices of primary care physicians, pain specialists, etc.
   1. Incentivize and offer trainings for healthcare providers in order to better utilize the technology and electronic health records available to them, which will then improve the coordination between all healthcare team members.
   2. Incentives have been offered to this point, but Delaware Public health has found that providers still underutilize the capacity they have in their Electronic Health Records (EHR). Therefore, restructuring and reevaluating incentives or mandating better utilization of HER is necessary in order to create this systemic change.
2. Establish a working group to research to capacity of expanding the PACE model to include younger populations or ensure that all the eligible elderly individuals who require nursing-home level of care have the opportunity to benefit from the program. The group should look at the current population’s outcomes, as well as the cost of expanding the model to a larger population, with different access to providers based on their location (i.e. - Kent and Sussex Counties).
   1. Senator Carper’s PACE Innovation Act, passed in 2015, allows the Centers for Medicare and Medicaid (CMS) to include PACE in demonstration programs that test how to improve health outcomes and reduce costs for seniors who are eligible for both Medicare and Medicaid. While the Act did not look at expanding to a younger population, it does allow more flexibility for CMS to include more elderly clients in the benefits of the model.
3. Establish an All Payer’s Claims Database by working through any potential conflicts or concerns with the 2012 legislation. Work to solicit support and sponsors and introduce the bill in the 149th General Assembly.
4. Institute a benchmark for quality care protocol, which would span insurance company reimbursement models, as well as healthcare provider’s baseline for care. The SIM grant should be the cornerstone of this effort.

10

1. Explore integrated payment models.
2. Standardize and incentivize the completion certificates for Diabetes and Chronic Disease self-management programs.
   1. Standardize learning outcomes for group self-management programs outside the hospital setting so that programs can be expanded, and all participants are able to receive completion certificates.
   2. Better utilize technology to reach a larger population by creating webinars for self- management programs.
   3. Incentivize program completion through insurers or employer.
3. Utilize Community Health Workers (CHW) in order to coordinate care for the patient, as well as conduct check-ins with the caregiver on topics such as their own healthcare and financial stability. This check-in will service to determine the feasibility and health safety of the patient staying in-home, versus requiring more assisted-living care.
   1. According to the National Conference of State Legislators, competencies for CHWs vary by state. Educational backgrounds vary among workers, ranging from some on-the-job training to formal community college-based programs that grant certification or an associate’s degree.3 Approximately 35 percent of workers who participated in a national study had completed high school, 30 percent had received a four-year degree, and 20 percent had completed some college requirements. About 7 percent reported they had less than a high school diploma, and another 7 percent reported they received a two-year degree. Some states mandate specific credentials for community health workers, a move that some believe will help integrate them into the health care system, raise the visibility of their roles, and obtain higher pay and reimbursement from insurers. Others fear this standardization will force out CHWs who do not have the resources to obtain the required credentials[[19]](#footnote-19).
   2. Regardless of credentials, seven core roles exist for CHWs:

* Proving cultural mediation between communities and health and human services systems
* Providing informal counseling and social support
* Providing culturally appropriate health education
* Advocating for individual and community needs
* Ensuring that people obtain necessary services
* Building individual and community capacity
* Providing basic screening services

1. Adopt a standardize transition model to eliminate gaps or interruptions in care for patients transitioning from pediatric to adult care.

11

11

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3. Appendix B [↑](#footnote-ref-3)
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