



To: The Delaware Health Care Delivery and Cost Advisory Group
From: The Developmental Disabilities Council
Date: April 16, 2018
RE: Delaware Health Care Spending Benchmark

Thank you for the opportunity to provide information toward the process of developing a health care spending benchmark that will bring equity and access to the health delivery system in Delaware for people with disabilities.

The Developmental Disabilities Council, in response to the less than adequate health care delivery in Delaware, drafted a Health Care Position Statement (attached) that clearly states the system changes that must occur in order to begin to bring equity in health for people of all disabilities.

We understand that the intent of your work is to meant for “each patient to have a medical home where care is coordinated” and that “Care oversight is critical to raising the quality of care and lowering the costs” (Julia Pillsbury, DO, FAAP, FACOP, Dover, DHSS Web Site). We applaud that lofty goal.

Unfortunately, the current health system is so lacking for people with disabilities that, in order for Delaware to reach equity and quality care, a tremendous amount of system change needs to occur in addition to the transfer of care to a coordinated medical home.

The current system currently lacks, for people with disabilities across the life span, the following:

1. Access to Care, Physical, Technological, Cultural, and Programmatic
2. Accommodations, Including Environment and Communication
3. Adequate Transportation To and From Care
4. Available Community Care
5. General Respect by Clinicians
6. Excessive Pharmacy Prescribing Due to All of The Listed Issues
7. Dental Care for Adults Except in the Emergency Rooms
8. Coordination of Services by Primary Care Doctors
9. Appropriate Timeframes for Appointments to Ensure Quality Care



10. Equipment Needed for Appropriate Diagnosis and Treatment
11. Available Specialists in our Community Statewide
12. Insurance Acceptance by Clinicians Including Medicaid
13. Personal Support at Appointments
14. Accessible Weight Scales
15. Long Term Services and Supports in the Community
16. Coordinated, Personalized, Flexible Diagnosis, Care, and Treatment Across the Life Span.

An institutional bias does still exist in the system, including the supports and services, and in the beliefs, values, and education of our clinicians. Because of this, the end result is higher cost outcomes and less than adequate care. Because of this, people with disabilities do not find healthy living solutions in the community. They are forced to access care in the Emergency Rooms, not through choice but through necessity. They experience secondary health conditions either as a result of their disability or as a result of poor access to health care.

For those living in or below the Poverty level, the expectation that they will be able to afford co-pays for treatment and/or pharmacy needs is unrealistic, and frankly, ludicrous. People with disabilities' rate of unemployment in Delaware and across the nation stands at 80%, not through choice but because of societal ignorance and historical practice. Typically, they are banished to impoverishment and do not have the education or means to bring themselves to a position to be able to afford co-pays or cost-sharing for health care.

A path to measured outcomes of the work of efficient and responsible cost curtailment relies on reliable and valid data. The collection, analysis, and reporting of data concerning people with disabilities is lacking and always has been. The newest research literature begins to document health care use and expenses for this population but the population needs have changed considerably over the past four decades. What was once an institutionally confined group of people whose life expectancy was considerably lower than the general population, today's people with disabilities have moved into our communities and live much longer than ever before.

The newer data has just begun to collect information on this group of people. As noted in "Health Services Use and Costs for Americans with Intellectual and Developmental Disabilities: A National Analysis" by Glenn T. Fujiura, Henan Li, and Sandy Magana, "Although our data-based profile of the health of Americans with IDD has expanded since the 2001 report, it remains limited



in content and fragmented across sampling frames” and from the same research article “Thus, we are not without data on the health of Americans with IDD, the aggregate profile is sparse and notably missing representative data on health care costs. This is an important omission” (Published in the American Association on Intellectual and Developmental Disabilities Journal of Policy, Practice, and Perspectives, Vol. 56, No. 2, April 2018).

Finally, as noted in the April 2018 Disability and Health Journal of the American Association on Health and Disability, “Disabilities predicted greater housing instability, food insecurity, and economic stress and less work and income” in a study of homelessness (“Long-term Housing Subsidies and SSI/SSDI income: Creating health-promoting contexts for families experiencing housing instability with disabilities,” Zachary S. Glendening, M.A., Erin McCauley, M.Ed, Marybeth Shinn, PhD., Scott R. Brown, M.Ed.). From the same report, “If Housing Choice Vouchers increase access to SSI/SSDI income while also reducing rent burden among families with members experiencing disabilities, they may be a potent tool for improving health outcomes in this community” (Long-term Housing Subsidies and SSI/SSDI income: Creating health-promoting contexts for families experiencing housing instability with disabilities,” Zachary S. Glendening, M.A. Erin McCauley, M.Ed., Marybeth Shinn, PhD., Scott R. Brown, M.Ed.)

In order for the Health Care Spending Benchmark to responsibly contain spiraling per-capita costs in Delaware, Policymakers must realize that simple cost cutting measures will not be effective when addressing the needs of our citizens with disabilities. Not only is there sparse data from which to work, the lives and needs of this population have been and continue to change relatively rapidly; from high cost institutions to community care. A health care system that has not yet caught up with the needs and informed preferences of this population cannot reflect validly what the costs are or may be in the future. And, in order to effect positive health care change, a holistic societal approach must be taken. Employment, housing, transportation, personal supports, accommodations, and the availability of insurance coverage must be considered and improved in order to effect change.

Should you not take our remarks into account with all of the issues listed above, the final Health Care Benchmark will result in a more expensive delivery system rather than a cost efficient one. Our community is not expendable, nor do we exist in the margins. We are valuable members of the state of Delaware and you must take us into account.



Delaware Developmental Disabilities Council 2015 Position on Health Care

Position Statement

All people of Delaware must be able to access health care and health-related services, including oral health care and eye care. Treatment must encompass the whole person with dignity. Emphasis must be placed on self-determination, access, affordability, quality, and accountability. Health care and health-related services should include:

- Personal choice and autonomy supported by Physician expertise.
- Increased awareness among people with disabilities of the steps they can take to develop and maintain healthy lifestyles.
- Early evidence-based screening/diagnosis/treatment for disabilities.
- Extreme caution in the prescription and use of psychoactive and psychotropic medications and informed consent must precede the use of such medications.
- Increased knowledge among health care professionals and provision of tools to screen, diagnose, and treat the whole person with a disability with dignity. This includes times of emergency management and recovery.
- Full access to disease prevention and health promotion services.
- Full access to disease prevention and oral health promotion services.
- Physical access to medical and dental environments including all equipment and machinery that may be needed to complete a thorough examination and assessment.
- Access to health clubs in the community.
- A comprehensive array of health, rehabilitation, personal, and support services.
- A Back-Up system of support services that is accessible to people across the disability spectrum 24/7.
- Affordability, portability and continuity of coverage to and from group, individual and government plans.
- Equity in coverage between mental health and physical health benefits. At all times, treatment should be voluntary with an informed choice on the part of the beneficiary. Parity should not make it easier to force people into accepting “treatments” they do not want.
- Medicaid Waivers that support people appropriately, no matter their disability.



- Studies and/or surveys should occur with direct input from people with disabilities concerning health care and health-related service needs, access, and quality.
- The inclusion of people with disabilities on hospital boards and others.
- An independent, impartial review board that includes people with disabilities to review problems as they arise.
- An appeals process when disagreements exist.

Discussion

The Delaware Developmental Disabilities Council supports the full inclusion of people with disabilities in all facets of community life; this includes the choice to be healthy. The Council believes that it is the responsibility of all Delaware citizens to improve the quality of life for everyone who lives here by promoting health and well-being.

It is accepted that people who take advantage of preventive care and maintain healthy lifestyles are less costly to the health care and dental care systems and the government than people who are not afforded the opportunity to do so.

According to the U.S. Surgeon General, “Today, 54 million Americans, or one in five people, are living with at least one disability, and most Americans will experience a disability some time during the course of their lives.” People with disabilities are more likely to experience secondary diagnosis as a result of their disability.

The January 2012 “The Plan to Achieve Health Equity for Delawareans with Disabilities” states “One critical area is the wide spread inequity in the area of health – in terms of access to services, the quality of service available and delivered, and the health outcomes experienced by individuals with disabilities.”

In addition, *The Current Landscape for Disability and Health in Delaware – A Public Health Assessment Report* as included in “The Plan to Achieve Health Equity for Delawareans with Disabilities” “details the disproportionate burden of disease experienced by Delawareans with disabilities through a review of health data and highlights the findings of a survey of physical and programmatic access barriers that continue to exist.”

Also included in the 2015 report from the Center for Disabilities Studies are the results of the 2013 Public Health statewide assessment of the population with disabilities in



Delaware. “The data indicate that compared to counterparts without disabilities, adults with disabilities are:

- more likely to report a delay in seeing a doctor due to cost (19.8% vs. 11.3%),
- more likely to be obese (39.7% vs. 23.7%),
- less likely to be physically active in the past month (59.7% vs. 80.6%),
- more likely to be current smokers (25.1% vs. 18.4%), and
- more likely to report chronic conditions of diabetes (20.4% vs. 7.0%), coronary heart disease (13.4% vs. 2.9%), and depression (33.8% vs. 10.1%).”

Considering all of this information, the Developmental Disabilities Council believes it is past the time for equity in our health care, dental care, and health-related service systems.

Recommendations

Delaware must:

- 1) Establish a fair and equitable health care, dental care, and health-related service system that will allow full access to those same systems.
- 2) Develop a coordinated system in which people with disabilities will be able to receive general health care and dental services ongoing or as needed.
- 3) Develop and coordinate an educational requirement of all physicians, dentists, and health-related clinicians and professionals who practice in the State of Delaware on disability.
- 4) Develop and coordinate an educational option and/or opportunity for people with disabilities on disease prevention and health maintenance.
- 5) Provide accountability of services of health care in Delaware on behalf of consumers of that same system.
- 6) Increase incentives that would create a larger health care work force; such as, increased wages that reflects cost of living increases, benefits that support workers and families, increased educational opportunities for workers to enhance the quality of their work.
- 7) Develop a Back-Up/emergency system for the State’s personal attendant service program.
- 8) Develop a State and local emergency operations plan that includes the needs of people with disabilities of all ages to ensure the safety and well-being of these same people in times of emergency management and recovery.



- 9) An independent, impartial review board that includes people with disabilities to review problems pertaining to health care as they arise. Members should participate with vigor.
- 10) Advocate for people with disabilities to be full members on health related Boards, Commissions, and committees such as, the Delaware Health Care Commission, the Architectural Accessibility Board, the Delaware Human Relations Commission, the Oral Health Coalition, and the Delaware Academy of Medicine.