



Virginia Department of
Behavioral Health &
Developmental Services

Developmental Disability Health Support Network

DDHSN Concept Paper

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Background

For nearly 20 years, Virginians involved in the care of individuals with intellectual and developmental disabilities (IDD) have identified the need for and barriers to community-based health supports. The concept of Regional Community Support Centers (RCSCs) was the brainchild of a parent-facility partnership, at the Northern Virginia Training Center (NVTC). This piloted clinic-based program was established in 1996, and funded by special appropriations via the Virginia General Assembly in 1998.¹ Since its inception, and in subsequent status reports, little has changed in the identified program/resident needs or the recommendations for the RCSCs now operating from each of the State-based Training Centers (TC). Issues identified in these reports include

- The need to transition residents from long-term facility-based care to the community.
- The need to increase the support funds for clinic expansion and services.
- The need for increased training for community-based health care providers and service providers.^{2, 3,4}

The February 2014 *Developmental Disability Health Supports Network Proposal* was the culmination of months research, deliberation, and strategizing with state stakeholders in an effort to support the healthcare needs of individuals moving from TCs to their preferred community. As a result of this stakeholder-based effort, the team changed the name from Regional Community Support Center to the Developmental Disabilities Health Support Network (DDHSN), in an effort to better describe the mission. This proposal identified service needs and laid out a plan to expand the RCSC/DDHSNs:

- Maintain a centralized clinic-based approach providing services similar to those in the TCs, and offered by personnel formerly staffing the closed TCs.
- Continue to offer CEU based education for interested community providers.
- Enhance inter-disciplinary relationships with clinic and community providers to achieve a team-based model of care.
- Explore potential for alternate funding and incentives to grow the RCSC and support satellite clinics with similar programs and teleconferencing capabilities.

Subsequent to this report, the Department of Behavioral Health and Developmental Services (DBHDS) and advocacy groups have re-evaluated the proposal's objectives and implementation strategies. General consensus is that the goals of the earlier proposal stopped short of significant changes in structure. Specifically, the Commonwealth should take this opportunity to accelerate progress in the development of services, and develop a person-centered method for achieving true community-based integration. Further, additional specificity is required to address the relative stagnation of community-based IDD healthcare competence for healthcare professionals. Consequently, a revised proposal is needed and is submitted here.



Overview

As of 2010, 140,000 Virginians are estimated to have developmental disabilities; more than half of these have intellectual disability.⁵ In March 2010, nearly 1200 individuals resided in State-based Training Centers (TCs), 48% of whom have since transitioned into the community.⁶ Health care service coordination and provision is fundamental to maintaining the viability of this transition. The Developmental Disabilities Health Support Network replaces the Regional Community Support Centers in both name and function.

Conceptually, the DDHSN is a state-based infrastructure to ensure appropriate quality supports toward barrier-free, community integrated healthcare for people with intellectual and developmental disabilities. The DDHSN exists to provide person-centered services to meet the needs for those who choose to access its providers, and proactively seeks to ensure that former residents of Training Centers, large Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs-IID) and Nursing Facilities (NFs) with IDD and concomitant medical issues (or considered *medically fragile*), receive the right health services, at the right time, by the right providers. In the short term, the DDHSN will provide a supports solution that meets the region-based health needs for people who have moved into the community from a large institutionalized setting. The long-term goal of this initiative is mainstream practice and normative social policy through improved IDD education of health professionals. The purpose of this paper is to outline the short and long term objectives toward barrier-free community integrated healthcare for this population.

To date, one of the TCs, Southside Virginia Training Center (SVTC) has completed residential relocation and was officially closed June 30, 2014. Community transition for the residents of Northern Virginia Training Center (NVTC) is in process and targeted for final closure in June 2016. Specific to these closures, DBHDS developed a discharge process to ensure that each individual's medical/health support needs were identified and the appropriate services were coordinated prior to transferring to the community. Though adequate resources were located in the region served by SVTC (Region IV), adding depth by establishing a more robust infrastructure will enhance the individuals' ability to remain within their chosen communities.⁷

As of FY 2014, there were approximately 170 children (ages 22 and younger) and more than 1500 adults with IDD living in NFs and large ICFs.⁸ The DDHSN seeks to provide both region-specific supports and a statewide substructure to ensure the safe (from a health management perspective) community relocation of individuals wishing to leave their current residence, and minimize the potential for failed residential placements for children and adults with IDD. Further, it seeks to ensure depth to diversion possibilities, preventing long-term institutionalization.



Healthcare, Virginia, and IDD

Virginia has universal healthcare challenges that include an ever increasing aging population, a decreasing health workforce, and substantial rates of chronic disease.⁹ These issues are magnified for people with intellectual and developmental disabilities. Adults with IDD are at higher risk for developing chronic health conditions and often at younger ages than other adults. “Age-related diseases” such as Alzheimer’s and osteoporosis can occur as early as age 20 or 30.¹⁰ At the same time, life spans have lengthened with the enhancements in medical care and environment, while life-style related illnesses have escalated.¹¹ Like other Virginians, people with IDD are facing increased rates of obesity, hypertension, diabetes, and dyslipidemia.¹²

Barriers to care, as for many Virginians, include a lack of access to competent, quality, affordable, and convenient healthcare professionals. People with IDD may also lack the ability to fully participate in their healthcare. Limitations resulting in a lack of effective communication compound the ability of healthcare professionals to adequately assess the range of health conditions that affect people with IDD. Core curriculums for health professionals do not universally address these barriers resulting in both a real and perceived lack of preparedness to care for patients within the current community-based health infrastructure.¹³ Understanding these challenges and barriers, Virginia proactively looks to remedy this public health issue through education and creative solutions for healthcare delivery.

Dental Services

The most pressing public health service need to date is also the most costly. Dental services historically have usurped the health services funds available to the communities, leaving little resources available to fund other health initiatives. This has been in part because it is not fully included in the Virginia Medicaid state plan.

Adult dental services are limited to medically necessary oral surgery and associated diagnostic services, such as X-rays and surgical extractions. Preventive, restorative, endodontic, and prosthetic services (e.g. cleanings, fillings, root canals and dentures) are not covered for adults.¹⁴

The recent cut of public health dentists has exacerbated lack of regional access, resulting in inadequate dental services for all Virginians without dental insurance coverage, including individuals with IDD.¹⁵ Subsequently, a number of initiatives to support dental care throughout the state have attempted to address the needs of individuals with IDD.

A statewide Memorandum of Understanding (MOU) contract with the Virginia Dental Association Foundation (VDAF) has been secured with DBHDS. This affords 500 underserved Virginians access to dental care and enables care managers for people with IDD to refer qualified individuals for free dental services that included preventative, restorative, endodontic, and prosthetic services through their *Donated Dental Services* program. While this program provides access to individuals with IDD living in the community, the same “slots” are open to all



uninsured Virginians. Future MOUs will look to secure a specific number of slots or fiscal appropriation specifically to individuals with IDD. DBHDS has also requested participation of VDAF's members in an assessment survey looking at where resources and barriers exist, and to help identify dental expert "champions" who might be interested in developing a statewide educational consortium for health related services for people with IDD

Regionally, several initiatives will be piloted with the ultimate goal of integrating a community care model over several years. In Health Planning Region IV, for example (the Richmond and surrounding area), several dentists have submitted Requests for Proposals (RFPs) to contract with DBHDS as providers. Services by local dentists have historically received fee-for-service reimbursement through the funds allocated to the RCSCs and Medicaid when allowable. The rates for service have been historically high and unsustainable in the future. Optimally, the planned ID/DD waiver redesign will provide for preventative and restorative care, since it is well documented that good oral health is fundamental to overall health.¹⁶ In the interim, DBHDS has forged an agreement with Hiram W. Davis Medical Center (HD) to offer diagnostic, preventative, restorative endodontic, and prosthetic dental care to residents of the region with IDD for FY 2015.

The need for services affords the Commonwealth an opportunity to re-think the current fee-for-service model and explore capitated dental care for non-Medicaid covered services. A capitated model would ensure regular biannual exams and treatment for patients and guarantee payment for participating dentists. Additionally, a capitated dental model will allow for budgeting and planning towards meeting the other healthcare needs of the individual.

Health Planning Region II (Northern Virginia) provides dental services for the residents of both NVTC and the community. The service model differs from that of SVTC and provides some hallmarks of best practice that should be embraced by other region-based dental practices for individuals with IDD. These include the use of desensitization and distraction techniques, minimal sedation, and positive reinforcement.¹⁷ Options for maintaining this model within the community are being explored. At this time, DBHDS will look to establish many provider contracts to build a community network.

As an adjunct to this, options for piloting tele-dentistry are being explored in order to allow regional experts to provide guidance to local providers from a distance. An evaluation of the various regional care models and national best practices will help to shape considerations for uniformity and policy decision in an effort to optimally allocate scarce resources. Clinical experts and educators are being sought to determine best practice for individuals supported by various state programs/waivers. Two Virginia-based academic and clinically active dental champions have been identified and further communications are pending. Initiatives to ensure core-curriculum inclusion are also being explored.



Medical/Allied Health

The majority of people with IDD are not acutely ill and many lack the chronic medical conditions that require substantial healthcare provisions. Yet, like all Virginians, preventative care can provide opportunities for healthier, happier lives, and a reduction in the prevalence of chronic illness. Thus an interdisciplinary health promotion model, rather than a medical, diagnosis-driven model for healthcare may serve Virginians with IDD most effectively. At the same time, there are individuals within the population who have multiple chronic diseases to manage or are considered *medically fragile*. A strong and competent healthcare infrastructure will support health promotion and maintenance, disease management, and acute care diagnosis and treatment.

It has been the perception of the IDD service community to date that there is a lack of accessibility and competence among healthcare professionals to holistically manage the health needs of individuals with IDD. Though consistent with the literature, the extent to which this is a reality in Virginia is unclear. Therefore, a statewide survey of healthcare professionals is ongoing. A link to this internet-based survey has been provided to a wide variety of state-based professional organizations and university health professional education affiliates (participation requested by the Director of Health Support Services for DBHDS) for distribution. Organizations include: Eastern Virginia Medical School, George Mason University, Inova, James Madison University, Long Term Care of Virginia, Medical Society of Virginia, Old Dominion University, Opticians Association of Virginia, Physician Associates of Virginia, Radford University, Sentara Healthcare, Speech-Language Hearing Association of Virginia, The Medical College of Virginia, The University of Virginia, Virginia Academy of Nutrition and Dietetics, Virginia Academy of Physician Assistants, Virginia Association of Behavioral Analysis, Virginia Association of Nurse Anesthetists, Virginia Chapter American Massage Therapy Association, Virginia Chapter of the National Association of Pediatric Nurse Practitioners, Virginia Chiropractic Association, Virginia Council of Nurse Practitioners, Virginia Dental Association, Virginia Family Physicians, Virginia Nurses Association, Virginia Occupational Therapy Association, Virginia Optometric Society, Virginia Osteopathic Medical Association, Virginia Pharmacists Association, Virginia Physical Therapy Association, Virginia Psychological Association, Virginia Podiatric Medical Association, Virginia Society for Clinical Social Work, Virginia Society of Physicians and Surgeons, Virginia State Therapeutic Recreation Association, and Virginia Tech.

The survey will look to identify provider willingness, availability, comfort, barriers and needs relative to managing patients with IDD and invite providers to act as “champions” within their respective fields to develop a statewide network and educational consortium for health related services for people with IDD. Responses to the survey will help to identify regional accessibility, perceived barriers, and potential solutions. It will also help to determine the concrete needs of the provider and identify to some degree the level of interest in developing as indicated, cultural competence.



Region-based services begin with the identification of person-centered needs. Region IV's Training Center is now closed. Despite a lack of a specific clinic-based experience for follow-up care, this region was determined to have the resources to sustain a safe and supported community integration plan. Yet long-term planning for coordinated health supports may still be important in this region until there is strong evidence of widespread cultural competence. Therefore, data regarding the medical and allied health needs for Region IV residents have been requested from multiple sources. The pre-discharges and post-placement assessments performed by the Community Integration Managers (CIMs) of DBHDS, especially for the medically fragile will be reviewed. This information has been requested of the Director of the Community Integration. In addition, a temporary regional Team Leader will be hired and assigned the mission of identifying potential gaps in services for Southside residents. The gap analysis may include a review of the most recent post-discharge reports from all involved stakeholders and, when needed, a home visit for the purpose of a health assessment. Overall data to be reviewed will include identifying who within the region requires significant healthcare supports such as dental, medical, rehabilitative, nursing, psychiatry, and pharmacy services. At the same time, the Director of Community Operations and the Director of Community Integration within the department are assisting by obtaining from the Community Service Board (CSB) IDD directors and CIMs a list of region-based health service providers.

A similar gap analysis will be conducted post-placement for all individuals in all regions for those leaving the TCs, NFs, and large ICFs and include data to be retrieved from sources such as DBHDS, the Department of Medical Assistance Services (DMAS), community organizations, TCs, NFs, and private providers.

Based on the needs identified in Region IV, the provider availability, and the utilization of dental services over the first quarter of FY 2015, the DDHSN will take shape in the form of either a temporary local establishment to "house" clinic services, or home visit services and mobile clinics, or both. This "temporary" solution will likely exist several years before it is no longer needed; while we build a long-term infrastructure fortified by an interdisciplinary educational plan for both existing providers and student health professionals. The important concepts of this plan are:

- The service model is flexible, dynamic and driven by individual need-- not determined by environment.
Ex. An individual needs rehab engineering received by mobile unit/clinic/other.
- The model is person-centered.
Ex. Person *A* needs behavioral counseling and wheelchair maintenance; Person *B* needs passive range of motion and wheelchair maintenance-- All people will not get a fixed set of services.
- The model is cost effective.
Ex. Services will be coordinated with above criteria in mind--Not randomly structured.
- State resources are effectively and appropriately utilized.



Ex. New provider models will be investigated and piloted--Such as home care provider service and education.

Operationalizing these care models depends in part on the results of the survey. An over-arching concept to describe meeting the educational needs anticipated is discussed in the section below titled *Education*. There will also be a need for stakeholder involvement to address the specifics of what these ideas might look like within each distinct region. Further discussion of the model ideas above is addressed in the section titled *Health Care Coordination*.

Education

Person-centered, community-based, barrier-free services will ultimately depend on a healthcare system competent and comfortable with the care of people with intellectual and developmental disabilities. Growing this system will be achieved by securing the cooperation and commitment of state universities, health professional organizations, and state agencies to teach the didactic components specific to the needs of people with IDD, in addition to ensuring clinical rotations with community experts. Health professions include dentistry, medicine, nursing, osteopathy, physical therapy occupational therapy, speech therapy, social work, behavior therapy, recreational therapy, pharmacy, podiatry, ophthalmology, optometry, psychology, and perhaps alternative care disciplines such as chiropractic, nutrition, and massage therapy. Efficient, practical methods for achieving this educational framework include creating a consortium of schools and providers to construct and implement a didactic interdisciplinary course that could be taught online as part of college curriculums or modified to provide CEU offerings to working professionals. Community-based experts could be tapped to provide hands-on experience within their respective fields and incentives could be provided to facilitate participation.

In researching the background of relationships between state organizations and universities, the concept of “what’s in it for us” has been mentioned repeatedly. Beyond good citizenship and social responsibility, there is much “in it” for all parties. The future of healthcare is an interdisciplinary model.¹⁸ Healthcare education is moving toward interdisciplinary courses attended by medical, nursing, dental, social work, etc., students. Online education is accessible and widely available from a variety of settings cost- free. Sites such as *edX*, out of MIT and Harvard¹⁹, *Coursera* out of Stanford²⁰, and *Khan Academy*²¹ have already proven the efficacy and efficiency of web-based education. Having similar programs provided by Virginia universities as part of a closed circuit consortium-based network allows universities the ability to charge for credit hours without having to invent a new course for every university or pay separate professors for similar courses at each university. Curriculum structures can be set up so that assignments and/or interactive components are programmed to be self-graded. Because it is computer-based learning, the way in which this could be taught is limitless and far beyond dry PowerPoint slides. Perhaps it is a recorded class with participants or a mix of lecture and recorded clinical exams. While the didactic program would be cost effective for universities, it would be fairly impersonal for the students, thus it will be critical to require clinical/residential



rotations. These rotations could be accomplished within a variety of settings, with community-based experts, and within existing training centers. The structure of this curriculum is best left to the academic experts. Conceptually, however, there is both a social and financial payoff for university institutions to join forces in this venture. Additionally, community-based providers wishing to further their education and learn more about individuals with IDD could obtain CEUs from the same consortium. A variety of methods could be applied to finance this interest. Money to pay for CEUs might come from sponsoring organizations, grant funds, university generosity, or funds allocated to the DDHSN.

Technology in the form of telehealth support could be both a component of the educational process and an avenue to increase access to care, particularly as providers express a willingness to accept more patients with IDD. Both IDD expertise and diagnosis specific consults can be supported using telehealth systems. Several state-based agencies already have the communications infrastructure to support HIPPA-compliant services. DBHDS currently has purchased licenses for Adobe® Connect to increase and improve intra-agency communication. If successful, piloting this medium for clinician support may be a cost-effective and efficient resource not currently utilized. Despite the associated controversy around HIPPA compliance, experts agree that in many ways these technologies are no less secure than traditional storage of information and communication methods.²²

Interactive Audio-Visual Technology (IATV) for clinician support, however, is different than IATV for patient consultation. Clinicians frequently “consult” with colleagues in the form of the informal “curbside” inquiry. This may happen face-to-face, or by phone. Though no identifying information is shared, case information is shared for the purposes of confirming a clinician’s thought process or to seek guidance. Guidance may then result in a formal consult. Formal consultation affords the consultant an ability to assess the patient directly and bill for services. Using IATV for the purposes of “curb-siding” may be extremely helpful, but currently is not billable. Despite this, this communication is important and even essential as the Commonwealth looks toward increased community integration for people with IDD. Incentivizing this may also be important. Looking at the future of this mission, stakeholders must ensure that creative and legal incentivization is discussed. Direct consultation via IATV may also be a reasonable and effective strategy for increasing community-based supports, however the considerations are much more complex.

Tele-medicine services are covered services. Within the Commonwealth, there exists telemedicine equipment housed within various universities and satellite areas to support clinical assessment, some of which is underutilized or not utilized at all. An inventory of such equipment and redirection of current resources may be helpful in operationalizing telemedicine for people with IDD. It will be important to understand that reimbursement criteria are very specific. Definitions of terms and specific equipment must be well understood. Still in this day and age, tele-health and telemedicine are responsible and important considerations as the Commonwealth looks to expand access to care for individuals with IDD and the community at large.



Operationalizing DDHSN

The role of the Director of Health Support Services is to assist in the development and facilitation of a regional and statewide infrastructure to support the health needs of individuals currently residing in institutions that have or will be moving into local communities. As part of the oversight of the nurse in charge of Pre-Admission Screening and Resident Review (PASRR), the Director is also responsible for ensuring appropriate diversion to preclude the further expansion of individuals with IDD being placed in long-term care facilities as a result of their disability. It is not the role of the DDHSN to determine which persons should or should not be placed in the community or remain in long-term care facilities, this is strictly the role of the individual, the individual's family or authorized representative (AR), and his/her existing medical and IDD team. Beyond the overarching concepts described above are direct care recommendations that specifically entrust nursing with duties that would afford the Commonwealth with resources that may increase access to quality care, and foster improved communication with patients, families and multidiscipline specialties.

There is a great deal of consternation when seeking to design new service delivery models for individuals with IDD. Person-centered delivery must be designed around measurable and valued outcomes, and resource utilization must consider cost effectiveness. Though new research is demonstrating that preventative health care while often important for enhancing one's general well-being, it does not demonstrate a cost savings unless specifically targeting those most likely to develop illness.²³ Individuals with intellectual and developmental disabilities disproportionately have more health problems than the general population. Complicating this for some, is an inability to communicate disease-based symptoms.²⁴

Though avoidance of the medical model has been historically preferred by the IDD community and advocates', excluding the medical model is not without consequence. For the medically fragile, and for those who are at risk for developing chronic disease, regular health assessments and preventative care is critical. One cost effective approach to maximizing scarce resources is for Virginia to embrace the key messages and consider the recommendations of the Institute of Medicine's 2010 report: *The Future of Nursing: Leading Change, Advancing Health*. These include:

- *Nurses should practice to the full extent of their education and training.*
- *Nurses should achieve higher levels of education and training through an improved education system that promotes seamless academic progression.*
- *Nurses should be full partners, with physicians and other health care professionals, in redesigning health care in the United States.*
- *Effective workforce planning and policy making require better data collection and an improved information infrastructure.*
- *Recommendation 1: Remove scope-of-practice barriers. Advanced practice registered nurses (APRNs) should be able to practice to the full extent of their education and training.*



- *Recommendation 2: Expand opportunities for nurse to lead and diffuse collaborative improvement efforts.*²⁵

Health Care Coordination/Community

Important to the success of the DDHSN, irrespective of service provision, is nurse-based care coordination. Regional Baccalaureate prepared Registered Nurse Care Consultants (RNCCs) are critical to a strong health support network infrastructure. The role of the RNCC may include assisting in the implementation of current tools such as the Health Risk Screening tool (HRST) and Supports Intensity Scale® (SIS®) to create (or implement) a plan for utilization of an assessment algorithm to categorize the health acuity of persons moving from institutions into their regional communities. This categorization would help determine the individual needs for care and the extent to which RNCC oversight and direct the health management structure are needed.

An example might look like:

Tier I: Healthy, no acute medical/behavioral issues, requiring *Health Resource Management* (HRM) structure, biennial RNCC face-to-face evaluation, annual or biennial health screening by primary care provider (PCP) and dentist.

Tier II: Healthy, stable chronic medical conditions or behavioral issues (three or fewer diagnoses) requiring *Health Program Management* (HPM) structure, annual RNCC face-to-face evaluation, annual screening by primary care provider (PCP), consulting providers and dentist and as needed (PRN).

Tier III: Moderately stable chronic medical conditions or behavioral issues (four or more diagnoses), requiring an *Intermittent Primary Care Management* (iPCM) structure intermittently-monthly RNCC face-to-face evaluation until stabilized then quarterly, minimum annual screening by primary care provider (PCP), consulting providers and dentist, and provider visits PRN.

Tier IV: Medically fragile or complex individual utilizing many health supports, requiring multiple management skills from care givers regarding chronic medical conditions or behavioral issues (four or more diagnoses), requiring a *Primary Care Management* (PCM) structure; monthly RNCC face-to-face evaluation, minimum annual screening by primary care provider (PCP), consulting providers and dentist and provider visit PRN - 24 hr RNCC phone support availability.

A literature search of best practices and conversations with medical experts for those with IDD, and program directors (The Arc of VA, Virginia Network of Private Providers and Training Centers, etc.) guided the development of this example and provided the recommendations for RNCC/beneficiary structure ratios:



Primary Care Management: Low individual to nurse ratio.

Health Program Care Management: Medium individual to nurse ratio.

Health Resource Care Management: Ratio High individual to nurse ratio.²⁶

In addition to face-to-face assessments, RNCCs would work with both residential community providers and health care providers to ensure that the medical, dental, allied health, and rehabilitative needs are identified and met in a timely fashion, assist in the education of community provider staff, and work with community health providers to enhance their clinical understanding for what is “normal” for this unique individual with IDD. Finally RNCCs could serve as coordinators for Care Management teams, affording RNs the opportunity to work with trained medical assistants who would help manage case load day-to-day activities for which skilled assessment, evaluation, and high level decision making is not required. “Care Managers” would not serve the same function as “Case Managers”. They would instead augment the care provided to individuals and alleviate part of the responsibilities of the case manager by assuming various health and medical services.

Chief amongst the list of considerations of this structure remains the determination for how RNs would be hired, financed, and managed. While overarching state-based milestones should reside within the purview of DBHDS and the DDHSN, stakeholders must come together to determine operational objectives and structure. Other considerations that will be important for stakeholders to agree upon include determining what factors to consider when looking at case mix models for RNs, and the appropriate tool utilization for determining Tier placement. *We must remember that paramount to all aspects of the DDHSN, the mission is not to create a parallel healthcare structure, but a pathway to community integration.* The ability of the DDHNS to provide a wide variety of services, including dentistry and RN case consultation, to each region will be largely dependent on understanding the parameters of the waivers’ redesign and the care models proposed for the healthcare management of Medicaid funds. DDHSN has been appropriated only 1.3 million dollars to serve an average of 27,000 people per region.²⁷ The services offered by the DDHSN as stated here are conceptual frameworks and may change related to fund availability.

Health Care Coordination/Individual

While policy change relative to scope of practice is outside of the scope of this initiative, maximizing current policy is not. To augment access to quality care for the patient with IDD, all medical providers should be utilized to the fullest extent of their education and training. One consistently underutilized resource is the nurse practitioner. It is currently Virginia state policy that advance practice registered nurses (APRNs), specifically nurse practitioners, can provide care in collaboration with a physician irrespective of state locale. It is also current Virginia policy that this NP-Physician collaborative care team allows for a six-to-one ratio. Expert



physicians for individuals with IDD can consult with any number of providers (including NPs), and may also have specific collaborative agreements with up to six NPs.

The NP need not have his/her collaborating physician be an expert with diseases associated with the IDD population. NPs can open their own clinics and hire physician collaborators. If NPs were more likely to take on patients with IDD, this alone would increase access to care. Both NPs and physicians (or PAs) would all face the question of IDD competence individually, and would consult or not consult experts in IDD as needed. However, capitalizing on this resource, could provide primary care medical/health management across the state and, in particular, in areas where access to care is limited.²⁸ Unfortunately, there are barriers. Some result from regulation, some are at the behest of insurance companies -- specifically insurance companies charged with the allocation of state Medicaid funds. It is an important limitation to understand.

Medicaid reimbursement compared to other forms of insurance is low, thus many physicians have historically been more reticent to accept the Medicaid patient. Patients with IDD and/or chronic diseases typically need longer appointment times.²⁹ These longer appointment times are not well compensated for any provider. In general, reimbursement structures do not provide the revenue they once did. To survive, many independent primary care providers must see a volume of patients per day that covers overhead, while ensuring an adequate income. Longer appointment times and lower insurance coverage inherently impacts the bottom line such that the “adequate income” bottom line is greatly affected.

Virginia Medicaid reimbursement provides 100% compensation of their fee for service to both physicians and NPs.³⁰ It is well known in the literature and as common knowledge that nurse practitioners make less money than physicians. While the workload has in many respects become greater, reimbursement and subsequent return on investment (ROI) has diminished or remained flat for all primary care providers. As a result, many physicians are leaving medicine or choosing to provide medical care that is more specialized than primary care or family medicine. Nurse practitioners, however, continue to choose primary care, or would chose primary care if they could be reimbursed. (Even at low Medicaid rates - because Medicaid will reimburse at 100% - essentially meaning equal pay for equal work). This is not to say that nurse practitioners are the solution to the workforce shortage in the state or for individuals with IDD, but rather to say that ensuring this opportunity could be part of the solution.

Uniformly ensuring that NPs are reimbursed at 100% for all Medicaid patients with IDD (by requiring all third-party Medicaid managed care organizations to recognize NPs as billable providers consistent with the state Medicaid regulations) would afford the state nearly two for the price of one care, and help to ensure overhead expenses are covered such that clinics can remain operational. As mentioned, NP compensation is significantly lower than that of physicians. Median NP salaries in Virginia are approximately \$96,000³¹, while physician median salaries are approximately \$184,000³². Further, a review of the literature demonstrates that for



primary care, nurse practitioners have equal or higher outcomes relative to quality care and management.³³

The primary care structure must creatively ensure that the Commonwealth examines the utilization of all workforce personnel, versus seeking organizational constructs to solve people-oriented issues. It may also be time to look at dental hygienists to expand access to some dental services, especially where services are sparse. Pharmacists and pharmacy techs may need to consider the value of increasing their efforts to evaluate and educate on medication utilization and adverse reaction. Rehabilitative service providers may need to consider developing best practice, in-home education tools for ensuring maintenance conditioning, and behavioral therapists and psychologists may need to consider how they would work together to maximize the benefit of their skill set through care-giver education.

PACE-like models or Medical homes solutions require the right professional mix in the right places, whether in-home or in-clinic, providing services consistent with the individual's needs. Mixed care delivery models need to look to physicians, their physician assistants, and nurse practitioners to solve the access to care issue. As an adjunct to this concept, it will be important to track measurable outcomes data. Information should include data such as: avoidance of emergency department (ED) visits, stabilizing chronic conditions, reducing hospital admissions, stabilizing and/or reducing weights, stabilizing blood pressure, blood sugars, and blood lipid levels (along with other similar measures). The prospective cost savings for nurse care management and NP led primary care management may be difficult to assess in light of a lack of comparable infrastructure and physician-driven primary care, but it stands to reason from the available literature that it is a care model that may substantially benefit Virginians with intellectual and development disabilities.

Financing, Institutions, and Other Matters

To be certain, the rare individual will not be successful in transitioning into inclusive community settings. DDHSN will work with stakeholders to identify this early and intervene as needed to minimize risk to the individual. Success should be measured by the work of all stakeholders to ensure that such a situation is identified and acted upon early. Success, however, should not be measured by the choice of a more restrictive setting if it is identified that the individual requires supports of a more restrictive residential setting.

It is impossible to create any system that affects numerous entities without considering the financial implications. It is also impossible to create financial structures without systems planning. It is the goal of the DDHSN to work with other agencies and organizations to operationalize and finance this substructure. Good public policy demonstrates the ability to utilize scarce resources under good stewardship, maximizing “bang for the buck.”



With these ideas in mind, we should look not only to the experts in IDD healthcare, but also to those willing to become experts, as we establish and finance systems that serve a potentially vulnerable and underserved population.

Conclusion

The mission of the DDHSN is predicated on the notion that a parallel healthcare system for individuals with intellectual and developmental disabilities is wrong for patients, wrong for providers, and wrong for Virginia. The concept of a health network is a stepping-stone on the path of statewide integration. Methods for achieving integration include the identification of willing healthcare providers, the compilation of a regional statewide resource directory, and the normalizing of supporting individuals with IDD through widespread education via universities and continuing education programs. Creative utilization of resources in terms of personnel, programs, and equipment will all need to be considered for a robust DDHSN to develop and ultimately dissolve as healthcare providers become more willing and able to care for people with IDD within their usual day-to-day practice.

Next Steps

The next steps are not in sequential order; some need to be performed simultaneously.

- Develop an interventional timeline
- Internal stakeholder review of plan
- External stakeholder review and public comment
- Re-convene stakeholder work group to operationalize plan
- Hire part-time or full time RN for Region IV
- Guide part-time RN to conduct home assessments of individuals who are medically fragile
- Develop service needs list and implementation plan for Region IV
- Assimilate/interpret survey data
- Make recommendations from survey data
- Begin to develop/strengthen university and expert relationships
- Hire/re-direct expert with IDD to assist with education development plan
- Guide expert in the development of core curriculum for education plans described
- Propose web-based interdisciplinary educational plan to universities
- Guide expert to develop CEU outreach of educational plan
- Develop dental plan dependent on waiver inclusion/exclusion
- Hire part-time RN for Region II
- Guide part-time RN to conduct home assessments of individuals who are medically fragile
- Develop specific service needs list and implementation plan for Region IV
- Draft decision brief to propose/include/fund tele-health-Adobe Connect



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