



## **Matheny School and Hospital, Incorporated Community Health Needs Assessment Report 2019**

### **Executive Summary**

Matheny School and Hospital was founded in 1946 and operates a special hospital, primary and secondary special education schools, day programs, group homes and an arts program, all focusing on children and adults with medically complex developmental disabilities. The specialty of the Matheny Hospital, located in Somerset County, New Jersey, is providing health care for medically complex developmentally disabled patients. While the focus of this needs assessment is the hospital, our commitment to our patients, clients and students is multi-focal and interdisciplinary across the continuum of Matheny's services.

**Matheny's mission:** To provide exceptional care and an optimal quality of life for children and adults with special needs and medically complex developmental disabilities.

**Matheny's vision:** To be the recognized model of excellence in the field of developmental disabilities.

**Our Goal:** To deliver exceptionally safe, high quality care to every patient, every day.

**Our Core Values:** Respect, Compassion, Professionalism and Integrity

Our community served is the population of people in the State of New Jersey with medically complex developmental disabilities. These disabilities may include: cerebral palsy, autism spectrum disorders, intellectual disabilities, processing/communication disorders, speech impairments, Down Syndrome, rare neurological disorders, mental illness, vision impairments, hearing impairments, traumatic brain injury, spina bifida, Lesch-Nyhan Disease, and fetal alcohol spectrum disorders.

This Community Health Needs Assessment Report [CHNA] describes our processes and findings in assessing our community's needs. We sought to elucidate perceptions of patients, families and other organizations regarding the medically complex developmentally disabled people living in New Jersey. We also sought to build upon previous needs assessments performed by Matheny and explore opportunities that may help meet the unmet needs of our patients and clients.



## **Community Health Needs Assessment 2019**

### **I. The Community Served**

Matheny serves the population of people in the State of New Jersey who have medically complex developmental disabilities. New Jersey’s Division of Developmental Disabilities defines a developmental disability as a chronic disability which:

- originated at birth or during childhood and is manifested before the age of 22
- is expected to continue indefinitely
- substantially restricts the individual's functioning in several major life activities
- is attributable to a mental or physical impairment or a combination of mental and physical impairments
- results in substantial functional limitations in three or more of the following areas of major life activity:
  - self-care
  - learning
  - self-direction
  - economic
  - receptive and expressive language
  - mobility
  - capacity for independent living
  - self-sufficiency
- effects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Disabling conditions may include: cerebral palsy, autism spectrum disorders, intellectual disabilities, processing/communication disorders, Down Syndrome, rare neurological disorders, mental illness, vision impairments, hearing impairments, traumatic brain injury, spina bifida, Lesch-Nyhan Disease, and fetal alcohol spectrum disorders.

According to the New Jersey Division of Developmental Disabilities (DDD) there are approximately 27,501 individuals living with developmental disabilities in our State. Somerset County, the county in which our hospital operates, is reportedly home to approximately 1269 developmentally disabled individuals. Of note, approximately 400 developmentally disabled people are noted by DDD to be receiving services out of state, with 362 of those individuals receiving out of state residential services

According to the most recent data from University of Colorado’s longitudinal database entitled “The State of the States in Intellectual and Developmental Disabilities”, in 2015, 11,764 New Jersey residents lived in supervised residential settings. 23,475 lived alone or with roommates, and 106,222 resided with family caregivers. Of those in residential settings, 2,729 lived in residential facilities with sixteen or more persons served. Six hundred seventy eight resided in



settings with seven to fifteen persons, and 8,357 resided in congregate settings with six or fewer residents or other residential settings.

DDD reports that the majority of developmentally disabled people in New Jersey do indeed live at their family home. Among the congregate settings in which others reside are: DCA-licensed homes, developmental centers, group homes, skilled nursing facilities, special hospitals, state psychiatric hospitals, supervised apartments, and other supportive housing.

## II. Persons Served

Matheny serves inpatients from 16 of the 21 counties in New Jersey, with the largest groups coming from Somerset (17.2%), Essex (6.2%) and Morris (14.1). Currently, 99 of these clients are inpatients at Matheny’s Special Hospital, which is licensed by the New Jersey Department of Health and Accredited by The Joint Commission. Thirty adults reside in Matheny’s community residences. Eleven students attend The Matheny School but live at home. The Schools’ total enrollment is 45 students. We also care for outpatients who utilize our dental services and sub-specialty medical services.

### States/Counties of Residence of Matheny’s Inpatients’ Families As of March 2019

State/County	Percent
<b>New Jersey</b>	
Somerset County	17.2%
Essex County	16.2%
Morris County	14.1%
Union County	10.1%
Bergen County	5.1%
Monmouth County	5.1%
Middlesex County	5.1%
Hunterdon County	5.1%
Passaic County	4.0%
Ocean County	3.0%
Cape May County	1.0%
Mercer County	1.0%
Cumberland County	1.0%
Gloucester County	1.0%
Burlington County	1.0%
Camden County	1.0%



<b>Out of State</b>	
New York	4.0%
Pennsylvania	3.0%
Maryland	1.0%
North Carolina	1.0%

Matheny’s inpatient clients range in age between the ages of 4 and 70 years of age. Thirty nine clients are 21 years of age or under. The remainders are adult clients who range in age from 22 to 70 years of age. There are 62 males and 37 females currently residing at Matheny. Almost 60% of the inpatients are white, 26.3% are black, 9.1% are Hispanic.

**Ages of Inpatients as of December 31, 2018**

Age	Count
over 50	1
45-49	1
40-44	3
35-39	14
30-34	15
25-29	24
20-24	16
15-19	13
10-14	7
5-9	4
under 5	1
<b>Total</b>	<b>99</b>

**Race of Matheny’s Inpatients**

Race	%
White	58.6%
Black	26.3%
Hispanic	9.1%
Asian	4.0%
Bi racial	2.0%

The great majority of Matheny inpatients and group home residents have cerebral palsy as their primary diagnosis. In addition to cerebral palsy, our patients may have other associated clinical conditions such as vision and hearing deficits, seizure disorders, intellectual disabilities and dysphagia, with resulting aspiration problems. Matheny also cares for patients with spina bifida, Lesch-Nyhan Disease (LND) and a wide range of uncommon neurological conditions including Rett syndrome, Angelman syndrome, Cornelia de Lange syndrome, Wolf-Hirshorn syndrome, and 4Q deletion syndrome. Lesch-Nyhan Disease is a rare x-linked recessive disorder associated with cognitive impairment, high levels of uric acid in the blood, kidney involvement, and the hallmark symptom – involuntary self-injurious behaviors. Matheny is recognized as one of the leading sources of information on care issues regarding Lesch-Nyhan Disease.



### **III. Matheny's Services**

Among its array of services, Matheny's hospital and outpatient program provides both inpatients and outpatients with the following services: primary and specialty medical care, dental care, wound and ostomy evaluation and treatment, seating and wheelchair clinical services, therapy services (audiology, occupational therapy, physical therapy, speech therapy, dysphagia diagnostics), and women's health care. Matheny's inpatients also receive recreation therapy and music therapy.

Within the hospital, the Matheny Center for Medicine and Dentistry (MCMD) is the locus of our outpatient services. While our inpatients receive most of their care in their residential rooms, specialty clinic services for our inpatients are also provided in the MCMD. In 2018, the 25 clinics in the MCMD had 884 outpatient visits and 1552 visits by our inpatients for a total of 2436 visits. The adaptive seating and dental clinics had the greatest numbers of visits.

Beyond the hospital and outpatient program, Matheny provides residential services in five community residences located throughout north central New Jersey. Each residence provides residential, personal care and nursing services for six adults with complex disabilities.

Matheny's day habilitation program located in Hillsborough and at our main campus in Peapack provides recreational and pre-vocational programming for adults with complex disabilities. At Hillsborough, participants include some individuals who reside at our hospital, some who reside in our community residences, and individuals who reside in their own homes or residences operated by other service providers.

Matheny's Arts Access program empowers individuals with disabilities to create art without boundaries. Through the use of innovative systems and techniques, clients can take part in the visual, performing and literary arts. Regardless of their disability, clients are provided with the tools and materials needed to produce complete pieces of work. On a daily basis, Arts Access fosters an environment of artistic creativity among the participating clients. The program improves the quality of life for the clients and those around them. In addition, Arts Access programming aids in changing the perception about the capabilities and talents of people with developmental disabilities.

### III. Identification of the Community's Unmet Needs

#### Secondary data

The *Somerset County Department of Human Services Advisory Council Report 2016-2020* published in September 2017, lists the developmentally disabled population as a priority population. Specifically, the report states that areas of consistent unmet needs among that population include:

- affordable housing;
- transportation;
- whole health care services;
- comprehensive services across the lifespan;
- qualified staff for all services; and
- productive employment transitional and daytime services.

Additional secondary data sources reviewed for this needs assessment include:

- [https://www.nj.gov/education/specialed/data/2016/Exiting\\_State.pdf](https://www.nj.gov/education/specialed/data/2016/Exiting_State.pdf)  
New Jersey Board of Education Special Education Data by Disability Type
- <https://www-doh.state.nj.us/doh-shad/resources/CHAcontactlist.html>  
New Jersey's publicly available searchable database of the NJ State Health Assessment data
- [https://www.state.nj.us/humanservices/ddd/documents/division\\_census\\_data\\_report\\_.pdf](https://www.state.nj.us/humanservices/ddd/documents/division_census_data_report_.pdf)  
New Jersey Division of Developmental Disabilities Data Report

#### Primary data

Previously, Matheny surveyed 51 agencies to determine how the health needs of people with disabilities in the state of New Jersey are being met. Fourteen of those agencies (27.4%) responded, but only seven identified themselves. They are:

- Abilities of Northwest New Jersey, Inc.;
- Alternatives, Inc.;
- Center for Family Support New Jersey;
- LADACIN Network;
- North Jersey Elks Developmental Disabilities Association;



- Princeton Child Development Institute; and
- Progressive Comprehensive Services, LLC.

As one part of that survey, participants were asked to rank seven types of services for persons with complex disabilities in terms of unmet need. Their responses resulting in the following ranking in decreasing level of need:

1. Medical and dental services
2. Transportation
3. Living quarters/residential services
4. Occupational/employment training and assistance
5. Therapeutic services
6. Availability of adaptive equipment and devices
7. Recreation

When asked for other important needs not included in the above list, there were five responses:

1. Mental health services.
2. Case management, health and wellness, and mental health therapy and psychiatry.
3. Outpatient psychiatric care.
4. Mental health services for people with physical disabilities.
5. Respite care.

From this survey, we learned based on other providers' estimates of the distance that their clients would travel to receive services, that more than one third would be willing to travel as much as 46 minutes to an hour for medical or dental services. The distances they would be willing to travel for other services (adaptive equipment, day programming, occupational training, therapeutic services or recreation) were somewhat less.

Among the major gaps in services or service limitations that the responding providers reported

1. Funding (general)
2. Transportation funding
3. Behavioral/Psychiatric/Medical needs
4. Housing options
5. Respite care for individuals with complex needs
6. Physicians with specialized training.

These and other data gathered in that survey have been instrumental in helping us better understand gaps in services for persons with complex disabilities, and they have helped to inform our strategic planning and our efforts described below.

## IV. Meeting the Community's Unmet Needs

In recognition of the identified unmet needs, particularly those in the areas of medical and dental services, residential services, therapeutic services, adaptive equipment and devices, Matheny has attempted to address those needs through: (1) health care education; (2) collaborative alliances and partnerships; (3) organizational transformation and expansion; and (4) awareness of, and engagement with, providers of related and collateral services.

### 1. Addressing unmet needs through health care education

Recognizing a need to ensure that the health care community beyond Matheny's walls is prepared to serve this population that, by its nature, has a narrower margin of health, Matheny actively trains future professionals in the field to work with this underserved population. This includes training and education of medical students, nursing students, students in the various therapies, and students in other allied health disciplines.

- ***Undergraduate Medical Students:*** Approximately 170 undergraduate third year Rutgers New Jersey Medical School medical students from visit Matheny annually during their pediatric clerkship. They get a 6.5 hour experience, totaling 1,112 “student-hours” of training provided per year. The students receive exposure to an interdisciplinary approach to providing care to the medically complex developmentally disabled patient. They meet with Matheny's medical staff, speech therapists, dieticians, arts program staff, a member of our quality improvement and patient safety team, a social worker, rehabilitation technology staff, adult services staff and a behaviorist. They also receive patient contact, including persons with Lesch-Nyhan Disease. In the context of a standardized patient exercise, the students conduct clinical interviews with patients who communicate in ways other than verbal. The exercise served as a model for the development of similar exercises in medical and nursing schools throughout the United States. A study published in *Academic Medicine* confirmed the short term impact on students' attitudes and perceived readiness to serve persons with complex developmental disabilities. Overall medical student evaluations of the one-day Matheny experience have consistently placed our program among the most highly rated pediatric clerkship experiences at Rutgers New Jersey Medical School.
- ***Residents:*** Residents in adolescent medicine at the Morristown Medical Center visit Matheny for exposure to medically complex patients with developmental disabilities. Approximately 10 residents rotate per year, each for about 2.5 hours, totaling 25 hours of





training. The residents meet with a member of Matheny's quality improvement and patient safety team, medical staff, a dietician, and a physical therapist.

- ***Nursing Students:*** Over 60 undergraduate and graduate nursing students from four NJ educational institutions – Raritan Valley Community College, Passaic County Community College, Seton Hall University, Somerset County Vocational Technical High School and Union County Vocational Technical High School spend more than 4,300 hours per year training at Matheny.
  - The nursing students from Raritan Valley Community College and Passaic County Community College complete their pediatric clinical rotations at Matheny, spending 12 hours a week on the hospital floor. Nursing students from Seton Hall receive training at Matheny's Adult Learning Center in Hillsborough as part of the community nursing program at the university that requires Bachelor of Nursing candidates to spend time at a variety of community nursing settings. Matheny also helps educate graduate nursing students from Seton Hall during clinical rotations and has participated in their thesis development exercises.
  - High school students at Union County Vocational -Technical High School shadow nurses throughout the day as preparation for a career in medicine.
  - All of the students learn unique skills such as how to communicate with non-verbal patients and how to dispense medications to people with complex disabilities, so they will be prepared if they later encounter persons with disabilities in other care settings.
- ***Students in the Therapies:*** Therapy majors from 32 US colleges and universities performed internships at Matheny in occupational, physical, speech, music and recreation therapy. The participating institutions were: Bloomsburg University, Boston University, Columbia University, Dominican College of Blauvelt, East Carolina University, East Stroudsburg University, Eastwick College, Elizabethtown College, Florida State University, Immaculata University, Ithaca College, Kean University, Marywood University, Mercy College, Misericordia University, Monmouth University, Montclair State University, Nazaraeth College of Rochester, Northeastern University, Ohio University, Rutgers University, Seton Hall University, Shenandoah University, Springfield College, Southern Methodist University, Temple University, University of New Hampshire, Touro College, University of Scranton, University of Miami, West Chester University, and Winston-Salem State University.
- ***Students in Social Services:*** Matheny also has an active internship program for social workers. The internship requires approximately 500 hours of supervised clinical clerkship with our patients. Colleges and universities supplying interns in recent years included the College of Staten Island, Monmouth University, and Rutgers University.
- ***Students in biomedical engineering:*** In 2016, thirteen biomedical engineering students at Rutgers University–New Brunswick immersed themselves at Matheny to help find



ways to improve clients' independence and quality of life. The teams worked with Matheny staff and clients and completed three projects:

1. a motorized headrest for wheelchairs to give people with cerebral palsy a greater range of vision and reduce their reliance on caretakers.
  2. an adjustable lateral support arm to give patients greater mobility with their bodies.
  3. a self-sterilizing intravenous pole for wheelchairs that is safe and retractable. It includes a cover with LED lights that emit ultraviolet light to kill bacteria.
- ***A cross-disciplinary alliance for training health care students:*** Recognizing the lack of disability-related training in medical schools, nursing schools, dental schools and other health care training programs, in 2007 Matheny convened educators from around the country to explore ways to promote the inclusion of disability-related content in all health care training programs in the United States. That roundtable event led to the establishment of a 501c3 organization dedicated to that purpose. The Alliance for Disability in Health Care Education, initially under Matheny's leadership, now boasts a membership of over 40 educators from leading universities and advocacy organizations. The Alliance has published papers in major health care journals, has presented at national and international conferences, participated in webinars, and in partnership with Ohio State University has published and disseminated a set of competencies to guide the design of disability-related curricula. Matheny remains active in the Alliance's activities.

## **2. Addressing unmet needs through collaboration, alliances and partnerships**

- Planning is coordinated with the NJ Division of Developmental Disabilities' plans for the expansion of services across the lifespan, and self-directed services.
- Matheny works with advocacy groups around NJ, such as the Alliance for Betterment of Citizens with Disabilities (ABCD), to improve the standing of our population with regard to state and federal resources.
- We engage other providers at a national level through the Pediatric Complex Care Association (PCCA). PCCA provides a platform for data benchmarking, information sharing, and conference-based education. Clinical data are collected quarterly and submitted to the Pediatric Complex Care Association; statistical reports are provided and allow us to compare to other organizations. These data assist in helping identify areas of strength and opportunities for improvement.
- Our Arts Access program coordinates with other similar organizations around the state for collaborative programming and events.

### **3. Addressing unmet needs through transformation and expansion**

- We continue to transform our hospital into a data driven high reliability organization that delivers exquisitely safe, high quality care to every patient every day.
- We work to develop our community programs outreach into a coordinated cross-departmental system to embrace more patients in our immediate area and beyond.
- We work with NJ resources to develop group homes for children and adults in the developmentally disabled community.
- In 2017, Matheny’s adult day health services department began the process of transitioning from an adult medical day care program into a day habilitation program. Matheny received our provisional certificate to operate a day habilitation program through the New Jersey Division of Developmental Disabilities in November 2017. With this approval, Matheny was now listed as a service provider through the DDD website. We began getting inquiries about our program in May of 2018. In addition, those adults currently enrolled in the adult medical day program began flipping into the fee for service supports program. The first clients flipped in May and by the end of the year, 24 of the 28 adults have successfully transitioned. By June of 2019, we anticipate the remaining clients will have transitioned. We continue to receive regular inquiries about enrollment opportunities in our day program. New Jersey’s adoption of the fee for service model has provided individuals with developmental disabilities the opportunity to choose the services they would like to receive. Support coordinators contact us regularly looking to find day programs that meet their client’s needs. The day program admission committee reviews all inquiries and enrolls clients when appropriate. In 2018, we enrolled one new client. Two additional clients have been enrolled in 2019 to date.

### **4. Addressing unmet needs through awareness of, and referral to, providers of related and collateral services**

Matheny cannot possibly provide the full extent of health care and human services needed by all people with disabilities in New Jersey. Therefore we have identified and collaborated with other facilities that serve those in the disabled community and have informed our potential inpatients and outpatients about facilities that can provide care that they need.

- The Atlantic Health Developmental Disabilities Centers are part of the Center for Human Development at Morristown Medical Center. The DDC offers diagnostic and treatment services for adults with developmental disabilities. Its staff includes board-certified internal medicine physicians and nurse practitioners who collaborate with developmental pediatricians, neurologists, psychiatrists, clinical nurse specialists, psychologists and

licensed professional counselors to provide comprehensive, integrated primary care and behavioral health services. Any adult with a developmental disability is eligible for DDC services but needs to be registered with the New Jersey Division of Developmental Disabilities (DDD). Patients include individuals who live with their families or in their own homes, supervised apartments, skills development homes with sponsors, or group homes with staff. DDC medical developmental disabilities services include: comprehensive medical and neurological evaluations; coordination of care; dental care; hospitalization at Morristown Medical Center or Overlook Medical Center with coordinated follow-up care and discharge services; neurological examinations and testing; primary health care for acute and chronic illness; referrals for genetic counseling and birth defects diagnosis and counseling; referrals for subspecialists (cardiologists, dermatologists, orthopedists, etc.); workshops and educational programs focusing on the special needs of people with developmental disabilities. The facility also provides behavioral health developmental disabilities services, and, at its child development and autism centers, provides pediatric developmental disabilities services as well.

- The Robert Wood Johnson Department of Family Medicine and Community Health operates the New Jersey Primary Care Research Network, a practice-based research network of nearly 120 primary care practices, more than 300 physicians, and approximately 750,000 patients. Participating practices are located throughout New Jersey in a variety of urban, suburban, and semi-rural settings.
- The Summit Medical Group employs more than 550 practitioners who support more than 80 medical specialties and services. In addition, SMG supports medical research to identify best treatments and practices for patients.
- Pleasant Run Family Physicians in Neshanic Station, NJ, provides care for patients of all ages, from newborns to geriatrics. It is part of the Atlantic Accountable Care Organization (AACO), a joint venture of Atlantic Health System and Valley Health System. It encompasses more than 1,800 physician participants in four regions of northern New Jersey, including Bergen, Morris, Sussex, Union, Hunterdon, and Somerset counties.
- The Richard Hall Community Mental Health Center in Bridgewater, NJ, is part of the Somerset County Department of Human Services. Its Office on Aging and Disability Services is a designated Aging and Disability Resource Connection (ADRC), designed to streamline access to long-term care support services, health promotion, and education. It links seniors, their caregivers, and adults with disabilities to the programs and services needed to remain independent and active in the community.
- Trinitas Hospital Behavioral Health Services is a comprehensive department of behavioral health and psychiatry operated by the Trinitas Regional Medical Center. Services are offered along with a full continuum of care, with specialized services available for adults, children, adolescents, and their families. In addition to operating a



95-bed inpatient facility for the adult, child/adolescent and mentally ill/developmentally-disabled persons, the hospital provides almost 200,000 behavioral health visits in a typical year.

## V. Progress in Addressing Needs and Implementing Strategies Identified in our 2016 CHNA

CHNA	Evidence of Compliance:
<p><b>1) Transform our hospital into a data driven high reliability organization that delivers exquisitely safe, high quality care to every patient every day.</b></p>	<p>All departments, teams, task forces, etc utilize data to improve their processes. Scorecards with key metrics have been implemented and data are shared with QI and PS Committees. Reports are provided to the Board of Trustees. Completed ORO 2.0 Self-Assessment process 5/2017. Ongoing staff education regarding HRO and the science of patient safety using tools such as HFMEA, RCA, TeamSTEPPS and CUSP. We are developing and implementing a Patient Safety Program for direct care staff members and are providing training in Lean Six Sigma.</p>
<p><b>2) Maintain our Accredited status with The Joint Commission.</b></p>	<p>We continuously prepare for our triennial survey and maintain survey readiness through our Continuous Survey Readiness Committee. Surveys are unannounced and we anticipate our next visit within the next year. We subscribe to The Joint Commission Resources’ online Accreditation Manager Plus program that allows us to document our status with each standard. The standards crosswalk to CMS Conditions of Participation.</p>
<p><b>3) Develop our community programs outreach into a coordinated cross-departmental system to embrace more patients in our immediate area and beyond</b></p>	<p>Change in Hillsborough from DOH adult medical day care to DDD day program. New group home location. Seating Clinic. Rehab Technology. Provide PT/OT/ST/Education through Department of Education to children who are unable to attend school. Strategic planning.</p>
<p><b>4) Coordinate our Arts Access programs with other similar organizations around the state.</b></p>	<p>Several of the clients’ artwork have been exhibited in galleries at Rutgers NJ Medical School in a collaborative exhibit with several other similar organizations. JSDD in West Orange, ARC of Mercer contracted with us to help them set up program. Arts Unbound, CSA two year</p>



partnership funded by Kessler. See Arts Access Calendar of Events 2017 attached.

**5) Continue to work collaboratively with healthcare educational programs across the State to improve the perception and ability of caregivers with reference to our population.**

Matheny continues to train all third-year medical students from Rutgers NJ Medical School; we provide training to nursing students at the Associates, Bachelors, and Masters levels; and we have internship agreements with over 100 educational programs.

**6) Work with NJ resources to develop group homes for children and adults in the developmentally disabled community.**

Strategic planning process includes the development of children and adult group homes. Pursued funding avenues for group homes.

**7) Continue to work with advocacy groups around NJ to improve the standing of our population with regard to state and federal resources.**

ARC, Association for Betterment of Citizens with Disabilities, New Jersey Developmental Disabilities Council, New Jersey Hospital Association, Pediatric Complex Care Association, Disability Rights New Jersey, Alliance for Disability in Health Care Education

## Conclusion

This report seeks to identify the unmet needs of our medically complex, developmentally disabled community and plan for how Matheny will meet those needs. We have built upon the goals set in our last CHNA and hope to continue this work into the future as meeting the needs of our community and persons served is truly a work in progress requiring continuous quality improvement and planning.