CHILDREN AND YOUNG ADULTS WITH MEDICAL FRAGILITY:
A Population Needs Assessment
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This report was commissioned by St. Mary's Healthcare System for Children.

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Executive Summary

Children and young adults with medical fragility are a growing, high need population in New York State and nationwide. Currently, an estimated 24,000 individuals with medical fragility under age 35 are enrolled in New York State’s Medicaid program; this population is estimated to grow at a rate of at least 5 percent per year.

With advances in medical technology, an increasing number of children with medical fragility are surviving past infancy and early childhood into adolescence and even adulthood. As such, the population with medical fragility is not only growing, but also aging. Approximately 9,100 young adults with medical fragility age 12-25 in New York’s Medicaid program are or will soon be “aging out” of pediatric programs and services.

Individuals with medical fragility have a wide range of complex medical conditions which require intensive, ongoing support from multiple specialty providers, and often require continuous skilled nursing care. As children with medical fragility get older, they lose access to specialty pediatric programs and services that they relied upon as children. This is reflected in utilization patterns of transitioning young adults – most notably through reduced utilization of home nursing services, increased utilization of institutional services, and movement away from pediatric programs and providers.

At the same time, parents are aging, and caring for a child with intensive medical needs at home becomes more challenging, and sometimes impossible. Yet few services exist, either in the home or in a residential setting, targeted to the medically fragile young adult population. For families navigating the transition of their young adult “aging out” of pediatric programs and services, this can lead to heartbreaking choices. And, at some point, most children and young adults with medical fragility who have skilled nursing needs and are unable to direct their own care will require some form of residential placement as parents age to the point where they are no longer able to care for their children at home.
Few providers are suited to meet both the medical and social/developmental needs of young adults with medical fragility; this is particularly true for residential settings. While it is difficult to determine the exact capacity of providers and programs that specialize in serving this population, it may be fewer than 100 total beds statewide. As a result, families experience long waits when seeking needed services, and many are faced with options that are poorly suited for their children. These capacity shortages will only get worse, as life expectancy of children with medical fragility continues to improve and the population of young adults with medical fragility continues to grow.

Young adults with medical fragility and their families face daunting circumstances. The transition from childhood to young adulthood is a tumultuous time for all adolescents; for those with medical fragility, it often throws families into crisis. New York needs a range of service options to ensure that young adults with medical fragility are getting the most appropriate care in the least restrictive setting. Care and care settings must address the social and developmental, as well as the physical needs of young adults, and enable them to stay in their communities and connected to their families. To meet the growing need, New York State will need a range of service options, including both in-home services and age-appropriate residential settings targeted to young adults with medical fragility.
About St. Mary’s Healthcare System for Children

Established in 1870, St. Mary’s became New York City’s first children’s hospital, and today remains the City’s only pediatric post-acute care facility caring for the region’s most critically ill and injured children. St. Mary’s is one of only a handful of organizations throughout the country that is dedicated to providing intensive rehabilitation, specialized care, and education to children with medical complexity and life-limiting conditions.

With a mission to improve the health and quality of life for children and families with special needs, St. Mary’s serves thousands in greater New York City and Long Island through a network of inpatient, community, and home care programs. St. Mary’s 97-bed inpatient facility, which is licensed as a skilled nursing facility, features 24-hour respiratory and medical coverage, and an inpatient case mix that more closely resembles that of a children’s specialty hospital than a skilled nursing facility. More than half of our inpatients require some level of respiratory support. State-of-the-art respiratory equipment enables St. Mary’s to admit children with greater respiratory needs, including those who are fully dependent on ventilators.

As a vital safety-net provider, St. Mary’s is one of New York State’s largest providers of long-term pediatric health services. St. Mary’s operates various long- and short-term home and community programs, a licensed home care services agency, a certified home health agency, and comprehensive case management. Additional centers of excellence include our Pediatric Day Healthcare Program, Center for Pediatric Feeding Disorders, Early Education Center (medical special education preschool), and St. Mary’s Kids at Roslyn, a dynamic therapy center and sensory integration facility.

With more than 140 years of institutional experience and expertise in caring for children with medical complexity, St. Mary’s is a leading authority and pioneer in pediatric healthcare. Over the last four decades, St. Mary’s has created the nation’s first pediatric palliative care program, NY State’s first long-term home healthcare program for children, the state’s first special needs certified home health agency for children and young adults with medical complexity, NYC’s first certified pediatric traumatic brain injury program, and the state’s only interdisciplinary program for pediatric feeding disorders.
About Manatt

Manatt, Phelps & Phillips, LLP is a preeminent law and consulting firm, combining legal excellence, public policy acumen, and industry savvy. Manatt Health, a division of Manatt, Phelps & Phillips, LLP, is a fully integrated, multidisciplinary legal, regulatory, advocacy and strategic business advisory healthcare practice. Manatt has one of the leading health strategy practices in the country, with more than 80 professionals (consultants, policy advisors, project managers, analysts and healthcare attorneys) providing analysis, knowledge and expertise to a wide range of healthcare clients including community health centers, academic medical centers, healthcare systems, mental health agencies and other institutional providers; post-acute care providers; national and regional payers; healthcare trade associations; philanthropic foundations and state and federal agencies and policymakers.

Manatt’s expertise and client engagements involve all aspects of healthcare, including delivery systems, processes, public and private coverage, financing and payment, and health information technology. Our healthcare team provides in-depth understanding of the complexities of government health insurance programs and federal and state financing mechanisms. We maintain an extensive federal and state policy tracking system whereby we keep current on emerging policy developments related to Medicaid and the Affordable Care Act at both the federal and state levels. This understanding, combined with knowledge of payer requirements and provider delivery systems, enables us to develop innovative and strategic solutions for both public and private sector clients.
Background

Children and young adults with medical fragility (“CMF” and “YAMF” or “C/YAMF”) are a heterogeneous group of individuals with intensive, complex health conditions requiring a high level of ongoing care and support. Many of these children were born with a combination of medical and in some cases developmental disabilities that require the use of technologies to support life, complex medical management, care management, developmental, educational and social supportive services, and continuous skilled nursing support either in the home or in a residential facility. Patients with medical fragility are an even more complex subset of the larger category of children with medical complexity – while roughly five percent of children are identified as medically complex, only one tenth of those (half of one percent) of all children meet the definition of medical fragility.

Historically, children with this high level of complex medical need have had relatively short life expectancy. As such, most programs, services and providers focused on serving this population specifically target or are limited to serving young children. However, with advances in medical technology, children with medical fragility are living longer, including into adulthood. As a result, the population of children with medical complexity is expected to grow by five percent per year,¹ and it is possible that those with medical fragility may grow at an even faster rate.

The challenges for families seeking care for children with medical fragility cannot be overstated. Children typically require a broad range of clinical supports and medical intervention; many require around the clock monitoring and care. To meet these needs, families caring for children at home must piece together multiple services and programs – special educational services, home modifications, private duty nursing services, specialized durable medical equipment – to supplement the intensive care provided by parents themselves. Even with support, parents caring for children at home typically struggle to manage care responsibilities for their child with medical fragility with demands of work and the care of other children, often with consequences for the financial well-being of the family. For some families, particularly those in urban areas, housing is a barrier; a walk-up apartment with limited space is not accommodating to a child in a wheelchair let alone more intensive technological needs.

These challenges are significantly compounded as children mature into adolescence and adulthood. Older children and their families face significant challenges securing care and services in an appropriate setting as they “age out” of programs, services and providers targeted to younger children. While young adults with medical complexity are more often able to make the transition to independence through a network of self-directed supports, this is rarely an option for those with medical fragility. And family caregivers themselves may be less able to care for children with medical fragility in the home as children’s bodies grow and become heavier at the same time parents age.

In New York State, most children and young adults with medical fragility are or will be covered by Medicaid, and many also are qualified for and receive services from the Office for People with Developmental Disabilities (OPWDD). The Americans with Disabilities Act and the subsequent Olmstead decision require public agencies to assure that

beneficiaries can receive services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” Pursuant to this requirement, and in the interest of children and families, it is imperative that public entities work to assure that there is an adequate range and supply of services and appropriate policies and programs in place for families seeking services for their children with medical fragility as they age.

In 2011, New York State launched the Medicaid Redesign Team (MRT), a comprehensive evaluation and planning effort seeking to improve various components of the state’s Medicaid program. As part of this effort, the Department of Health (DOH) and OPWDD convened the Medically Fragile Child Work Group (“Work Group”) to comprehensively evaluate the size, demographic and utilization characteristics of children with medical fragility, and the delivery system, programs and policy supports available to this population. The Work Group issued its report in 2013, which was the first such report produced in New York State.

This paper builds upon the Work Group report, by analyzing the needs of older children and young adults with medical fragility, changes in utilization patterns of children and young adults with medical fragility as they age, and the availability of services to meet the needs of this population and provide appropriate options for families. The remainder of this paper is dedicated to (1) documenting the number and characteristics of adolescents and young adults with medical fragility in New York; and (2) documenting service needs and service gaps as the population ages. We conclude that young adults with medical fragility, aged 12-25, are a significant and growing population in New York State, and that the state currently lacks adequate services in appropriate settings to meet their needs. The paper concludes with a recommendation that the state invest in expanding supports, including residential group facilities with full-time medical staff, to meet the needs of this population.

“The young adults are the hardest to place because they shouldn’t go to adult facilities, and pediatric providers would just have to transition them again…”

– CAH case manager
Profile of NYS Children and Young Adults with Medical Fragility

To understand the population of children and young adults with medical fragility in New York State, it is first necessary to specify how the population is defined and methods to identify the population using available data. While there is no standard definition of MFC/MFYAs, four “cardinal domains” for characterizing children and adults with complex medical needs have largely guided the discussion. The Children's Hospital Association (“CHA”) recognizes four cardinal domains used to characterize children with medical complexity (“CMC”):

1. Chronic, severe health conditions
2. Substantial health service needs
3. Major functional limitation
4. High healthcare resource utilization

In this context, various approaches have been developed by clinicians, researchers and policymakers to operationally define this population and analyze their characteristics and needs. These approaches focus on the relatively larger population of medically complex children. When analyzing the subset of this population with medical fragility specifically, it is necessary to utilize even more targeted approaches.

Definitions, Data Sources and Methods

The 2013 Medically Fragile Work Group report provided the first comprehensive profile of children with medical fragility in New York State and provides a good starting point for analyzing the population of adolescents and young adults with medical fragility. The Work Group, convened by the New York State Department of Health (DOH) and the Office for People with Developmental Disabilities (OPWDD), defines the population of children with medical fragility to include children under age 21 with chronic or debilitating condition(s), and who:

1. Are technologically-dependent for life- or health-sustaining functions, and/or
2. Require a complex medication regime or medical interventions to maintain or improve their health status, and/or
3. Are in need of ongoing assessment or intervention to prevent serious deterioration of their health status or medical complications that place their life, health, or development at risk.

To identify and profile children meeting this definition using Medicaid claims data, DOH (on behalf of the Work Group) used a complex methodology to identify individuals for inclusion into the MFC population. Consistent with the concept of the four cardinal domains discussed above, the Task Force considers utilization of specific programs and service provider types, patient diagnoses, and Per Member Per Month (PMPM) healthcare cost consumption as

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1 Berry, J et al. “The Landscape of Medical Care for Children with Medical Complexity.” Children’s Hospital Association, June 2013. Available online at http://www.childrenshospitals.net/cmclitreview
part of the criteria for inclusion of children into the population identified as experiencing medical fragility. A child is included into the population if they meet one or more of the following criteria:

1. Enrollment in the Care at Home Waiver (CAH I/II, III, IV, and VI) regardless of diagnoses or other criteria, or
2. Utilization of one or more specialized services, programs or providers defined by the Task Force and one or more diagnosis in the list of 96 diagnosis defined by the Work Group, or
3. Average Per Member Per Month (“PMPM”) costs of $10,000 or more and have one or more diagnosis in the list of 96 diagnosis defined by the Work Group.

This paper expands the methodology used in the Work Group to include the population of young adults with medical fragility. It also updates the Work Group methodology to reflect changes in the policy environment and programs used by children and young adults with medical fragility since 2012 when the Work Group analysis was conducted.

Specifically, to make the definition fully applicable to young adult populations, it is necessary to modify the criteria for item 2 above to include non-pediatric programs and services that are utilized by young adults, in addition to those that the Work Group adopted in their definition which is targeted to children. It is also necessary to update the definition to reflect recent changes in the payment and delivery system landscape as a result of the expansion of Medicaid Managed Care and changes in waiver programs and the Long Term Home Health Care Program. The adjusted definition includes, along with the services specified in the original Task Force definition, measures of Personal Care utilization, managed long-term care plan enrollment, Medicaid Service Coordination utilization, Adult Day Health Care utilization, and the Bridge to Health and Nursing Home Transition and Diversion Waivers.

For purposes of this project, it is important to understand the profile of adolescents nearing the age when they will need to transition out of programs and services targeted to children, and young adults over age 21 who have aged out of these programs and services. By comparing the population with medical fragility before and after “aging out,” we can identify changes in how children with medical fragility utilize services as they age. To that end, the age range of interest is expanded to include young adults 21-25 (recently aged out), and an older “aged out” cohort age 26-35. Population and utilization data are reported for children age 12-20 and young adults age 21-35, and for the aging out target population age 12-25.

**Population Profile**

Using the definition, data sources and methods described above, we find that there are 13,200 children with medical fragility below age 21 in New York State Medicaid, and 10,700 young adults with medical fragility age 21-36. Of these, 9,100 are in the “aging out” population age range of 12-25.

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4 Services, programs and providers considered include pediatric specialty nursing homes, hospitals and clinics, Intermediate Care Facilities, HCBS Waiver, OHHA and private duty nursing utilization, and the Long Term Home Health Care Program (LTHHCP)

5 The Work Group defined a list of 96 diagnosis to use as a tool to help identify the MFC/YA population. See Appendix X for a list of diagnostic codes used by the Work Group.

6 Additional information on Work Group methodology obtained through author communication with NYSDOH staff, Fall 2015.
Children and young adults with medical fragility are distributed all across New York State, relatively proportional to the total population of Medicaid beneficiaries. Because of their small numbers, in many parts of the state the population is sparse, adding to the challenge of finding age appropriate services. However, even in densely population areas, services to meet the needs of the population are in short supply.

**Figure 1: Map of “Aging Out” Population with Medical Fragility Age 12-25, by County**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Population Count</th>
<th>Age Group as % of Total C/YAMF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population with Medical Fragility, Age 0-35</td>
<td>23,800</td>
<td>100%</td>
</tr>
<tr>
<td>“Aging Out” MF Population, Age 12-25</td>
<td>9,100</td>
<td>38%</td>
</tr>
<tr>
<td><strong>Children with Medical Fragility, Age 0-20</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Age 0-11 (younger children)</td>
<td>7,700</td>
<td>32%</td>
</tr>
<tr>
<td>- Age 12-15 (adolescents)</td>
<td>2,500</td>
<td>11%</td>
</tr>
<tr>
<td>- Age 16-17 (adolescents near aging out)</td>
<td>1,200</td>
<td>5%</td>
</tr>
<tr>
<td>- Age 18-20 (young adults aging out)</td>
<td>1,800</td>
<td>7%</td>
</tr>
<tr>
<td><strong>Young Adults with Medical Fragility, Age 21-35</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Age 21-25 (young adults recently aged out)</td>
<td>3,600</td>
<td>15%</td>
</tr>
<tr>
<td>- Age 26-35 (aged out young adults)</td>
<td>7,000</td>
<td>29%</td>
</tr>
</tbody>
</table>

Children and young adults with medical fragility are distributed all across New York State, relatively proportional to the total population of Medicaid beneficiaries. Because of their small numbers, in many parts of the state the population is sparse, adding to the challenge of finding age appropriate services. However, even in densely population areas, services to meet the needs of the population are in short supply.

**Figure 1: Map of “Aging Out” Population with Medical Fragility Age 12-25, by County**
Children and young adults with medical fragility require a range of services, programs and providers, provided by multiple funding streams and implemented by multiple government agencies. Many services are Medicaid financed, including services provided through waivers, often with oversight by the New York State Department of Health. Additional key services are provided through OPWDD, and enhanced support for educational services available to children with disabilities. This patchwork of financing streams and agency oversight requires families to piece together care plans and services – typically a delicate challenge. Children and young adults with medical fragility often qualify for services through OPWDD. Among the “aging out” population with medical fragility age 12-25, 75% are qualified for OPWDD services. Yet, this population is a small minority of those receiving OPWDD services. About 10% of all OPWDD qualified Medicaid beneficiaries age 12-25 are medically fragile. Within the Medicaid population the proportion is even smaller: only 0.5% of all Medicaid beneficiaries in this age range are medically fragile.

Table 2 indicates that there is significant variation by age in the use of key Medicaid paid services and programs. Specifically, it is notable that:

- **Key programs, services and providers used by children are not available to young adults.**
  - Seventeen percent of children with medical fragility below age 12 and ten percent of adolescents age 12-20 with medical fragility use the Care at Home Waiver program, which is not available over age 18.
  - Fifteen percent of children with medical fragility use specialty pediatric hospitals and clinics, which are designed to serve children under age 21. Only 3% of young adults over age 20 receive services from these providers.

- **Younger children overall use a higher level of skilled nursing services than adolescents, but young adults are more likely to use institutional care.**
  - Younger children with medical fragility are almost twice as likely to use Private Duty Nursing (PDN) services than adolescents or young adults, suggesting that as children age they are less likely to receive a high level of nursing services in the home.
  - Younger children with medical fragility are slightly more likely to use institutional skilled nursing services than adolescents or young adults, though aged out young adults (and older adults) use institutional care at a higher rate. Forty percent of aged out young adults age 25-36 utilize skilled nursing facilities or intermediate care facilities.

- **Adolescents and young adults are much more likely to participate in the HCBS waiver, as many as 45% (three times the rate for children) in the recently aged out group age 21-25.**

- **All age groups use Medicaid Service Coordination (MSC) at relatively high rates, though twice as many adolescents and young adults use it when compared to younger children.**
It is important to keep in mind that, as described in the population analysis methodology section above, children and young adults are largely defined into the population identified as medically fragile based on their utilization of these key programs and services, in combination with one of 96 diagnoses indicating medical fragility. For example, a patient with one of the 96 identified diagnoses and any utilization of a specialty pediatric hospital or clinic would be defined into the medically fragile population. In addition, any patient with one of the 96 identified diagnoses and more than $10,000 PMPM average monthly Medicaid claims costs would be defined into the population regardless of whether or not they utilized one of these identified services.

As Table 2 above illustrates, only a subset of children and young adults with medical fragility utilize skilled nursing services, either in an institutional setting (SNF/ICF) or in the home (PDN). These patients are of particular importance, as they are the highest utilizers of high cost continuous nursing services. For purposes of this paper, patients with medical fragility using SNF or PDN services are identified as the “high need target population.” This population faces particular needs as they age out of specialty pediatric services and programs. Table 3 presents this high need subgroup by detailed age categories.

### Table 2: Share of Population with Medical Fragility by Age Group and Use of Key Medicaid Services, Programs and Specialty Providers

<table>
<thead>
<tr>
<th>Service/Program</th>
<th>Age 0-11</th>
<th>Age 12-20</th>
<th>Age 21-25</th>
<th>Age 26-35</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total C/YAMF</strong></td>
<td>7,700</td>
<td>5,500</td>
<td>3,600</td>
<td>7,000</td>
</tr>
<tr>
<td><strong>Waivers/Care Management</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care at Home</td>
<td>17%</td>
<td>10%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>HCBS Waiver</td>
<td>14%</td>
<td>30%</td>
<td>45%</td>
<td>40%</td>
</tr>
<tr>
<td>Medicaid Service Coordination(^7)</td>
<td>29%</td>
<td>60%</td>
<td>65%</td>
<td>48%</td>
</tr>
<tr>
<td>Other (LTHHCP(^8), B2H, NHTDW)</td>
<td>2%</td>
<td>2%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td><strong>Institutional Care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialty Pediatric Hospitals/Clinics</td>
<td>15%</td>
<td>6%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Skilled Nursing Facility (SNF) or Intermediate Care Facility (ICF)</td>
<td>31%</td>
<td>25%</td>
<td>30%</td>
<td>39%</td>
</tr>
<tr>
<td><strong>Private Duty Nursing (PDN)</strong></td>
<td>20%</td>
<td>11%</td>
<td>10%</td>
<td>7%</td>
</tr>
<tr>
<td><strong>Managed Long-Term Care Plan</strong></td>
<td>0%</td>
<td>0%</td>
<td>4%</td>
<td>7%</td>
</tr>
<tr>
<td>(MLTC/PACE/MAP)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>OPWDD Qualified</strong></td>
<td>41%</td>
<td>75%</td>
<td>75%</td>
<td>59%</td>
</tr>
</tbody>
</table>

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\(^7\) Medicaid Service Coordination (MSC) was not included as a service among those used to identify children with medical fragility in the DOH Medically Fragile Work Group definition. For this analysis, in light of the need to expand the definition to include young adults and changes in other key programs such as LTHHCP, MSC was included when it appears in concert with one of the 96 identified diagnoses alongside other programs and services used to identify the population with medical fragility.

\(^8\) In the DOH Medically Fragile Work Group report, a significant number of children were identified as participating in the Long-Term Home Health Care Program (LTHHCP). Subsequent to the production of that report, this program and the representation of the program in Medicaid enrollment and claims data changed such that only a small number of patients can be identified as participating in the program. It is likely that many of these patients appear as users of Medicaid Service Coordination (MSC) in this analysis.
In total, we find that there are 9,500 of these target population individuals age 0-35 statewide, of whom 5,500 are children age 0-20 and 4,000 are young adults age 21-35. Two-thirds of these children and young adults utilize skilled nursing facilities, and the other one third received skilled nursing services in the home. This population is also of interest in terms of the need for age-appropriate residential placement options. Those currently residing in skilled nursing facilities may need placement in more age-appropriate settings, and the vast majority of those currently using skilled nursing in the home will need residential placement at some point in the future as parents age.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Population Count</th>
<th>Age Group as % of C/YAMF High Need Target Pop</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Need Target Population, Age 0-35</td>
<td>9,500</td>
<td>100%</td>
</tr>
<tr>
<td>&quot;Aging Out&quot; High Need Target Population, Age 12-25</td>
<td>5,800</td>
<td>61%</td>
</tr>
<tr>
<td>High Need MF Children, Age 0-20</td>
<td>5,500</td>
<td>58%</td>
</tr>
<tr>
<td>- Age 0-11 (younger children)</td>
<td>3,700</td>
<td>39%</td>
</tr>
<tr>
<td>- Age 12-15 (adolescents)</td>
<td>800</td>
<td>8%</td>
</tr>
<tr>
<td>- Age 16-17 (adolescents near aging out)</td>
<td>400</td>
<td>4%</td>
</tr>
<tr>
<td>- Age 18-20 (young adults aging out)</td>
<td>600</td>
<td>6%</td>
</tr>
<tr>
<td>High Need MF Young Adults, Age 21-35</td>
<td>4,000</td>
<td>42%</td>
</tr>
<tr>
<td>- Age 21-25 (young adults recently aged out)</td>
<td>1,200</td>
<td>13%</td>
</tr>
<tr>
<td>- Age 26-35 (aged out young adults)</td>
<td>2,800</td>
<td>29%</td>
</tr>
</tbody>
</table>
Documentation of Existing Services and Service Gaps

As the discussion above illustrates, children and young adults with medical fragility rely on a range of different community based and institutional services and providers for their care. However, it is not clear that the families accessing specific services represent the scope of those who might seek to utilize them but are unable to due to limited capacity. It is also unclear to what extent specific providers currently accessed by families of children and young adults with medical fragility have the social, educational, and developmental characteristics suited to this age group.

While there are many services that may be part of the overall plan of care for a child or young adult with medical fragility, for purposes of this paper the key medical service types that are most critical to the care of this population fall into four categories: medical residential facilities (SNFs), non-medical residential facilities (group homes), home care agencies, and care management/care coordination agencies. (Additional services that are not paid by Medicaid, such as educational supports, are not included in this analysis due to a lack of available data.) These services can be understood as a continuum of options for children and young adults with medical fragility, depending on the level of need and the capacity for care to be provided in the home. It is crucial that young adults and their families have a range of options available to them as care needs and/or family circumstances change over time.

To understand the universe of existing services and providers, we gathered quantitative information about the universe of providers, services provided, and capacity of providers by type in New York State. However, providers who specifically target their services to children and young adults with medical fragility are a very small subset of that overall universe. To gather information about the capacity and characteristics of these specific providers, we relied on key informant interviews with eight providers known to provide these targeted services, across the continuum from medically residential (skilled nursing facilities), non-medical residential (group homes), home care and care management. These providers were able to provide a depth of qualitative information about their own organizations and other organizations they work with or are aware of in the environment, as well as the landscape of challenges facing providers and the families they serve. We also interviewed three family members caring for children with medical fragility who are nearing the point of aging out.

Home Care

Many families prefer to have their child with medical fragility at home if at all possible, and most families care for their children at home for at least part of their lives. However, it can be challenging for families to enroll their children in the most appropriate programs and to obtain the reliable home nursing services they need. The challenges compound as children age. The DOH and OPWDD Care at Home (CAH) waivers which provide case management and

“Nurses could be with a child for sometimes 14 years. The children age out now, they are now adults and the reimbursement rate is less and then you start begging the nurses.”
– Home nursing agency manager

“We can’t get enough services in the home. We might get them approved but that doesn’t mean we have the bodies to provide those services.”
– CAH case manager
expanded services to children with medical fragility are not available for young adults with medical fragility over age 18. It is notable that other waiver programs without the same rich benefits as CAH, such as HCBS, and care management services such as Medicaid Service Coordination, are also used heavily by both children with medical fragility under age 18 and young adults with medical fragility over age 18, as evidenced by the utilization profile above. Changes to the current waiver programs are on the horizon. The state has announced its intent to transition all populations to managed care, and to replace care management services provided through waiver programs with pediatric health homes. The impact of these changes is yet to be seen.

Regardless of whether children participate in Care at Home or another waiver or care management program, securing reliable nursing services can be a challenge. New York, as is the case nationally, suffers from a shortage of qualified private duty nurses, meaning that many families caring for children in the home have difficulty finding adequate and consistent nursing services. Though this issue has been helped somewhat by an increase in home nursing rates for children that went into effect in 2007, once a child turns 18 the nursing rate falls and nurses may seek opportunities to work with a younger child to earn the enhanced rate.

According to providers working in this field, due to shortages of qualified private duty nursing, some families turn to less skilled home health support through the Consumer Directed Personal Assistance Program (CDPAP), which allows families to hire and manage their own home care workers regardless of the worker’s level of medical training. This is especially common when children age out and the reimbursement rates drop for their nurses, interrupting access to skilled nursing care. In rare cases, CDPAP can enable a young adult capable of self-direction to transition to independence; however, because of complexity of need and common co-occurring cognitive limitations, this is rare for the population with medical fragility. Recently, New York State amended the CDPAP program to allow for close family members – including parents – to receive the same hourly rate for care provided to a medically fragile family member as an unrelated worker would receive under the program. While this new CDPAP policy will provide additional support for families, it does not replace the need for skilled nursing services.

Even when adequate and reliable home nursing support is available, family caregivers bear a significant burden managing their children at home, and many are unable to do so, or to continue to do so as they age. Some families, particularly low income families living in urban areas, may be unable to bring their children home even if they want to, as they may not be able to obtain housing with enough space to accommodate a child who is dependent on technology, for example. In addition, if both parents work, or in single parent families, it can be extremely challenging to manage

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“**When I don’t have a nurse, I’m the nurse. I’m doing all of his skilled care and I’m, at this point, coordinating all of his skilled care. I do everything.”**

– Parent of 16 year old with medical fragility cared for in the home

“Parents tell me, ‘I need to go to work, and I can’t go to work because when I go to work I get called out from my job to take care of my child who’s now sick, and I have to take him to the hospital, and my job is not taking that likely. So I’m at risk of losing my job.’”

– Pediatric nursing home provider

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10 29 N.Y. Reg. 6-7 (Dec. 5, 2007) (codified at N.Y. Comp. Codes R. & Regs. tit. 18, § 505.8(g)(6))

the needs of a child who requires intensive 24/7 care, even with substantial home nursing support. If a nurse is unavailable, parents often have no recourse but to take up those duties, regardless of how it may impact their employment and the financial well-being of the family.

**Care in Residential Settings**

Currently, New York State has a significant number and range of residential treatment providers, serving over 100,000 patients in skilled nursing facilities and as many as 38,000 more in OPWDD certified residential settings with some on-site medical and supportive services. However, appropriate options for children and young adults are far more limited – less than 500 skilled nursing beds in New York serve the pediatric population. And according to the New York State Department of Health, nursing homes in the state have an overall occupancy rate of 93%, and specialty pediatric nursing home beds are at full capacity, with weekly census averaging 97% occupancy.

<table>
<thead>
<tr>
<th>Provider/Program</th>
<th>Number of Providers</th>
<th>Capacity (Bed Count)</th>
<th>Patient Census</th>
<th>Occupancy</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Skilled Nursing Facilities</em>¹⁴</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Standard Residential Beds</td>
<td>618</td>
<td>112,861</td>
<td>104,960</td>
<td>93%</td>
</tr>
<tr>
<td>- Pediatric Beds</td>
<td>9</td>
<td>487</td>
<td>472</td>
<td>97%</td>
</tr>
<tr>
<td>- Ventilator Beds</td>
<td>54</td>
<td>1,116</td>
<td>1,004</td>
<td>90%</td>
</tr>
<tr>
<td>- Pediatric Ventilator Beds</td>
<td>4</td>
<td>56</td>
<td>56</td>
<td>100%</td>
</tr>
<tr>
<td><em>OPWDD Residential Services</em></td>
<td>371¹⁵</td>
<td>38,000¹⁶</td>
<td></td>
<td>11,000 person residential request list</td>
</tr>
</tbody>
</table>

Group residential settings may be more appropriate for children and young adults than an institutional facility, when adequate medical supports are available. However, OPWDD group homes are also at capacity – the residential request list currently includes 11,000 individuals, with roughly 1/4 indicating that they need residential services within two years. Almost 1,400 (12%) of the individuals on the residential waiting list are young adults age 18-22, and an additional 500 (5%) are children age 0-17.¹⁷

While group homes may be a desirable option for some families, the typical group home setting is often ill-equipped to meet the medical needs of children and young adults with medical fragility. While group homes typically do have medical staff on site, they do not have the capacity to serve children and young adults with intensive medical needs.

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¹³ Pediatric beds are facilities or units specifically designed for children under age 21. Children may be housed in general SNF beds that are not specifically identified as pediatric beds.
¹⁶ OPWDD February 2016
at the level that a one on one private nurse would. Even if a child theoretically could access private duty nursing in a family home, currently regulations\textsuperscript{18} prohibit private duty nurses from caring for their patients in a group home setting, as their services have historically been believed to be redundant with on-site medical supports.

Moreover, in addition to the challenges of finding a placement in the context of this under-supply, when considering residential treatment in either an institutional or a group residential setting, families must weigh whether the environment is suited to their child's social and developmental needs. A skilled nursing facility serving mostly geriatric patients is unlikely to be a suitable placement for a young adult, lacking age-appropriate educational and enrichment activities, or opportunity for social contact with peers.

While New York's nine pediatric nursing homes do provide a vital service as an appropriate setting for many children with medical fragility, they are only equipped to provide services until the age of 21. There are no skilled nursing facilities in New York State specifically designed to serve the young adult, or even non-geriatric adult, population. Pediatric nursing homes face a perpetual challenge of working with families to find placements for young adults aging out of their programs. In the absence of available options, young adults may stay in a pediatric setting past age 20, occupying a bed that was intended for and would otherwise be serving younger children and adolescents.

While supply is severely limited, there are a small number of specialty providers that do provide group residential settings in the community specifically designed for children and young adults. The earliest of these were developed in the 1990s and early 2000s. Organizations such as Angela's House and AHRC-NYC opened small group residential facilities that can accommodate children with intensive medical needs, including those who are technology dependent or require one on one skilled nursing support. Some of these settings are designed to accommodate younger children, and some focus on serving young adults. Openings in these facilities are rare and placements there are highly sought after by families. In total there are fewer than 100 such beds in New York State.

Families often wait years for a placement in one of these facilities. And, the majority of these beds are only available to children below age 21 under their current licensure.

Finally, a small number of residential schools are funded by the New York State Department of Education that provide medical supports appropriate to children and young adults with medical fragility in an appropriate social and developmental environment. However, as with all educational services, these schools can only be accessed by children under age 21. As such, these settings represent another case where aging out means that significant

\textsuperscript{18} Office for People with Developmental Disabilities General Overview Presentation, Changes to Separately Billed Services for People who live in Supervised and Supportive IRAs, CRs, and Family Care Homes, September 2015.
numbers of young adults and their families must transition out of a setting that meets their needs, into an environment where there are few comparable residential options available.

Regional/Geographic Considerations

Regional/geographic distribution of appropriate providers presents an additional challenge for families. As Figure 1 illustrates, children and young adults with medically fragility are distributed relatively proportionally across New York State. However, when reviewing the current landscape, we find that a disproportionate number of the residential settings appropriate for children and young adults with medical fragility in New York State are located in the New York City metropolitan area, placing a strain on limited capacity within the region. At the same time, families living upstate often have to travel significant distances to visit their child in a downstate facility, or as far out as Long Island where several of these specialty providers are located. In addition, home nursing provider supply upstate is often even more limited in than in New York City, though families in both regions report trouble securing adequate private duty nursing support.

Regional differences also impact whether families have the option to care for their children with medical fragility at home. Some families, particularly low income families living in urban areas, may be unable to bring their children home even if they want to, as they may not be able to obtain housing with enough space to accommodate a child who is dependent on technology. A walk-up apartment, or one with an unreliable elevator, is not appropriate for a child in a wheelchair let alone more intensive technological needs. Care managers report that as part of transition planning they sometimes conduct home visits to evaluate whether the layout of the home itself can accommodate the child, and tragically, some children simply cannot go home despite the family’s wishes.

I haven’t found anything nearby… where I would be able to see her and make sure she’s being properly taken care of and also the warmth of her family because that’s all she basically has.  
– Parent of 21 year old aging out of pediatric specialty nursing home
Conclusion

Children with medical fragility and their families face significant challenges managing a complex combination of medical, social and developmental needs. While a number of specialty programs and providers offer age appropriate service options to children, many of these are not available to young adults age 21 and over. As a result, appropriate care for young adults is often difficult or impossible to obtain.

The unique combination of needs that these young adults and their families face requires unique solutions. While a small number of specialty providers and organizations have specialized expertise serving this population, they are currently resourced to serve a fraction of the thousands of young adults with medical fragility in the state. As a result, families experience long waits for needed services, and many must make difficult choices between options that are not well suited for their children’s social, development and emotional needs.

Moreover, current capacity shortages will only get worse, especially as life expectancy of children with medical fragility continues to improve and the population of young adults with medical fragility continues to grow.

New York State must consider ways to expand service options and capacity of age-appropriate, community-based residential settings serving young adults with medical fragility, and opportunities to ease the transition in programs and services associated with “aging out.” Young adults with medical fragility and their families need a range of options from home care to age-appropriate residential group homes and skilled nursing settings to provide the most appropriate care in the least restrictive setting. Support from the state to increase the number and capacity of suitable programs and providers is the only way to accomplish this goal.

“There haven’t been programs targeted to the population, because a lot of these kids weren’t living this long so nobody was really paying attention to the need in terms of making funding available and thinking about what these young adults would need…”
– Specialty pediatric provider

“What we need is a definitive answer [about programs for children aging out] so the children can have quality of life, the families can have a quality of life … I’d say it’s a no man’s land… I personally do not know how to advise [anyone] other than to make sure… that the parents are thinking about, what do they want to do once the child has aged out?”
– CAH provider