



Caregiver Navigation for the Southern Tier

A Report of Community Needs
and Recommendations

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Context for this Report

The Southern Tier Health Care System (STHCS) has expanded its commitment to support caregivers in the communities it serves. STHCS has conducted a community assessment to gain a deeper understanding of the community needs and gaps relative to caregivers. Understanding of these gaps have been translated into a plan of action. STHCS will refer to this report, completed in March 2021, to advocate for increased funding to support their commitment to caregivers.

Other communities and national studies make the case for the need to support caregivers and speaks to the challenges in doing so. While unique to the Southern Tier, the assessment and recommendations outlined in this report are bolstered by the work of others. For example, the Caregiver Intensity Index Research by the Ralph C. Wilson Foundation, in surveying 479 caregivers in Southeast Michigan found the following:

- Only 30% of respondents were aware that services were available to support caregivers
- Most caregivers found the ability to speak with other caregivers to be very helpful (64%) or somewhat helpful (20%) but only 36% had ever done so
- Caregivers are buffered from stress when they feel informed (31%) and supported (28%)
- 76% of caregivers would consider using services if they were available
- Caregivers experience a lot of anxiety and depression, with younger caregivers experiencing the most (48% vs 25% for older caregivers)

The CDC, in “Caregiving for Family and Friends – A Public Health Issue” (January 2019) illustrates that the likelihood of providing caregiving to a family member is increasing over time. The pool of potential



family caregivers is declining (7 today, vs. 4 in 2030) and 20% of 45 – 64 years-olds who are not already providing care expect to do so.

Caregiving is hard on the caregiver. According to the same CDC report, caregivers often neglect their own health needs and 53% indicated a decline in their own health impacting their ability to care for their loved one. Caregivers also find it to be emotionally and physically demanding. If the caregiver is married to the person receiving care, the strain on the relationship is extraordinary, at 80%. Divorce rates are as high as 75% (US News, January 2019).

The recommendations in this report, if adopted, will be directly addressing the needs as expressed by the community itself and respond to the nature of the Southern Tier communities the STHCS serves. The primary goal stemming from this assessment is for the STHCS to be THE place to go for information and for navigation to services for caregivers and those they are caring for. Additionally, the STHCS will lead efforts to remove barriers impacting the caregiving experience. The plan that this report outlines relies on maintaining their full-time position and resources allocated to the efforts.

About Southern Tier Health Care System (STHCS)

Southern Tier Health Care System, Inc. (STHCS) was founded in 1994 as one of New York's first four rural health-care networks. Their mission is to improve the health and wellness of the rural communities served. A 501(c)(3) not-for-profit organization, STHCS is headquartered in Olean, N.Y., and serves Allegany, Cattaraugus and Chautauqua counties in the Southern Tier of Western New York. Working with 12 community partner agencies and hundreds of other collaborators, they create programs that identify and remove barriers to health care.

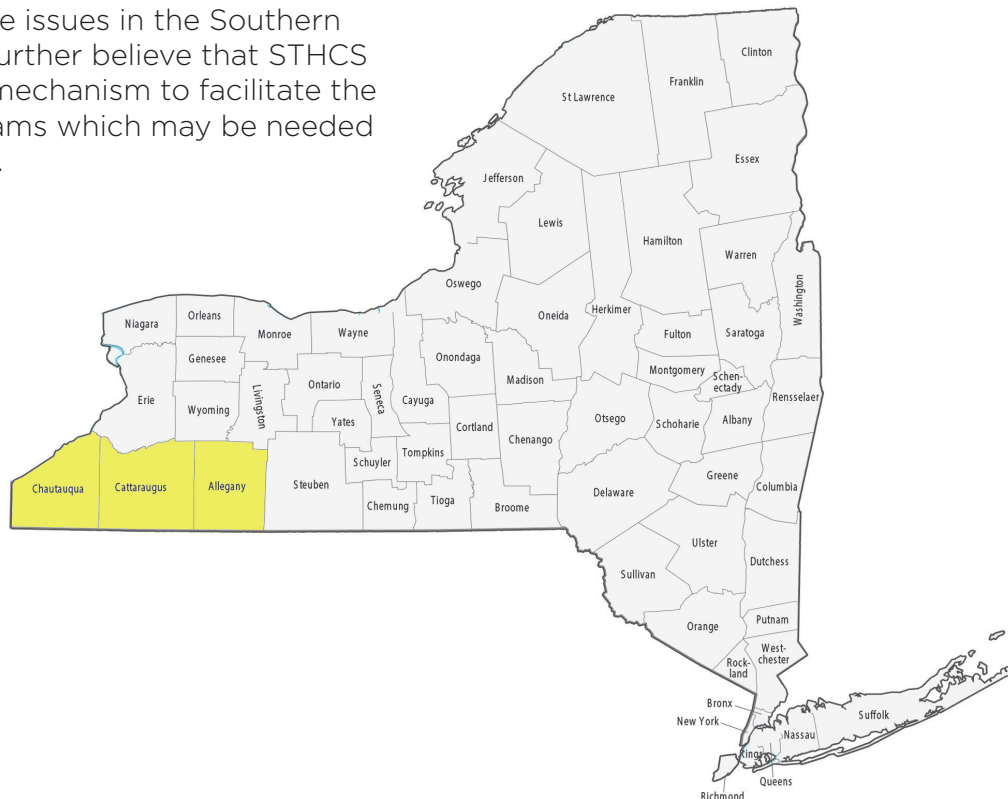
Their Vision is that comprehensive health needs of all people will be met through its facilitation of an accessible, seamless, quality system of providers and services. This will be accomplished by maximizing resources and cost-effective approaches to improve the quality of life.

Agencies and organizations affiliated with STHCS believe that their collective knowledge and experience is an effective resource to address health care issues in the Southern Tier region. They further believe that STHCS is an appropriate mechanism to facilitate the project and programs which may be needed to accomplish this.

STHCS accomplishes their strategies by maximizing resources and cost-effective approaches to improving the quality of life in the Southern Tier of Western New York.

Partners of STHCS utilize the rural health-care network to coordinate training opportunities, facilitate collaborative community health efforts, research and write grants, and other administrative tasks. STHCS is supported by funding from state and federal grants and private foundations.

STHCS is one of the leading community advocates for health, wellness, and safety in the Southern Tier. STHCS offers extensive health education and outreach programs for health benefit exchange and caregiver navigation, regional EMS training and oversight, community automated external defibrillator (AED) placement and compliance, child health and safety, care for survivors of sexual assault, safe sleep for infants, and opioid-overdose prevention.



STHCS Caregiver Navigator Project

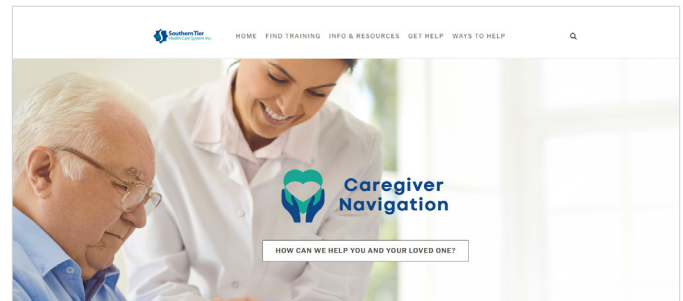
In support of STHCS' Mission, Vision and Beliefs, STHCS is looking to further support and address the dire needs of Caregivers in the Southern Tier counties.

An initial grant from the Ralph C. Wilson, Jr. Legacy Funds permitted the launch of STHCS' **Caregiver Navigation Project** in 2018 with a 0.5 FTE Navigator position. The Navigator successfully researched available caregiver resources within the communities of Allegany, Cattaraugus, and Chautauqua Counties and began providing digital or personal guidance to those caregivers who sought it. The Navigator also established a subdomain under STHCS' official website and built a social media presence to promote trainings and available resources to regional followers.

The Legacy Funds again funded the Caregiver Navigation Project in 2019 to sustain the 0.5 FTE Navigator position and support activities through May 2020. The project period focused on continuing as a resource for community guidance on available caregiver services, as well as providing relevant training opportunities for caregivers of elders and individuals with disabilities requiring assistance.

Through its early efforts with the Caregiver Navigation Project, STHCS knew that the continuation of the work was important to the community and that continuing to refine the program to have the biggest impact was essential. Given the increased activities and support required by the Navigator position, STHCS transitioned the Navigator position from a part-time to a full-time position in June of 2020, funded by the Ralph C Wilson, Jr. Foundation through May 31, 2022.

They also acknowledged that "making the case" for the program and full-time resources was essential to attract funding for sustaining



the supports for caregivers. Beginning in September 2020, the STHCS engaged in a community assessment process and strategic planning process, funded by the Ralph C. Wilson, Jr. Foundation. The intent was to ensure that future planning was based on a study of needs.

STHCS hired a consulting team to conduct an assessment of community needs and help to drive to recommendations for the future evolution of the Caregiver Navigation Project. The consulting team of Shari Rife (Ideas Realized) and Mary Beth Debus (Program Savvy Consulting) assessed the needs and identified gaps of caregivers across their service area and made preliminary recommendations. They then facilitated the process for the STHCS to develop a plan that will guide the Caregiver Navigation Project into the future.





Community Study

An Assessment of Caregiver Needs & Barriers

The consulting team of **Shari Rife (Ideas Realized)** and **Mary Beth Debus (Program Savvy Consulting)** completed an assessment of community needs and compared those findings to other studies conducted by trusted funders and national studies.

Methodology

The findings and recommendations are based on a community survey, interviews of six professionals working for entities providing support and resources for caregivers, and two focus groups of family caregivers (as described in the “Context for this Report” section).

It should be noted that the inclusion of all three of these methodologies was effective at exploring nuances that no one methodology alone would have properly highlighted. Due to COVID-19, all interviews and focus groups were conducted safely over Zoom.

Interviews

Southern Tier Health Care System reached out to agencies in the community noted for their supports for caregivers and older adults and requested them to participate in an interview. The following organizations were included in those interviews:

- Homecare and Hospice
- Alzheimer’s Association of WNY
- Cattaraugus County Health Department
- Allegany County Office for the Aging
- Cattaraugus County Department of Aging
- Office for Aging Services (Chautauqua)

The main topics addressed during the interviews were:

1. Services provided to older adults and caregivers
2. Most significant needs of caregivers
3. Activities that cause the most stress in caregiving
4. How supports are accessed and who is providing them
5. Barriers to asking for or receiving help
6. What educational programs are offered/requested
7. How services are promoted/advertised



Community Survey

While the interviews were being conducted, a survey was promoted across the region by the Southern Tier Health Care System and many local organizations who agreed to promote the survey on social media and with their clients.

The main topics of the survey were:

1. Demographic information so that a description of typical caregivers could be determined
2. Their relationship to the person being cared for and descriptive information of that person or persons
3. In what ways they are providing care to their loved one and how frequently
4. What, if any, professional services they are using with their loved one
5. What services are most important to them, and whether they are receiving those services
6. What causes the most stress in their role as caregiver



7. Barriers to receiving supports
8. How they learn about resources that may be available to them
9. Their desire for and participation in educational offerings

There were 36 responses to the survey and below is an overview of who responded:

- Where respondents lived:
 - 22.2% Allegany County
 - 58.3% Cattaraugus County
 - 5.6% Chautauqua County
 - 13.9% from Other
- Gender:
 - 97.2% females
 - 2.8% males
- Relationship to the caregiver:
 - 75% are taking care of one or more parents
 - 8.33% are taking care of a spouse
 - The remainder are taking care of other family members (siblings, children, grandchildren, nieces/nephews)
- Current status of caregiving:
 - 50% currently taking care of one or more loved ones
 - 41.7% previously had taken care of one or more loved ones

- 8.3% will probably be taking care of one or more loved ones in the future
- Who they live with:
 - 38.9% of the caregivers live with their loved one(s)
 - 55.56% do not live with loved ones
 - 5.56% sometimes live with loved ones
- How often they provide care:
 - 41.67% indicated they spend 30+ hours supporting loved ones
 - 33.34% indicated they spend under 8 hour supporting loved ones

Focus Groups

Two focus groups of three people each were conducted with women from Cattaraugus County. Two main questions were discussed in these 90-minute focus groups:

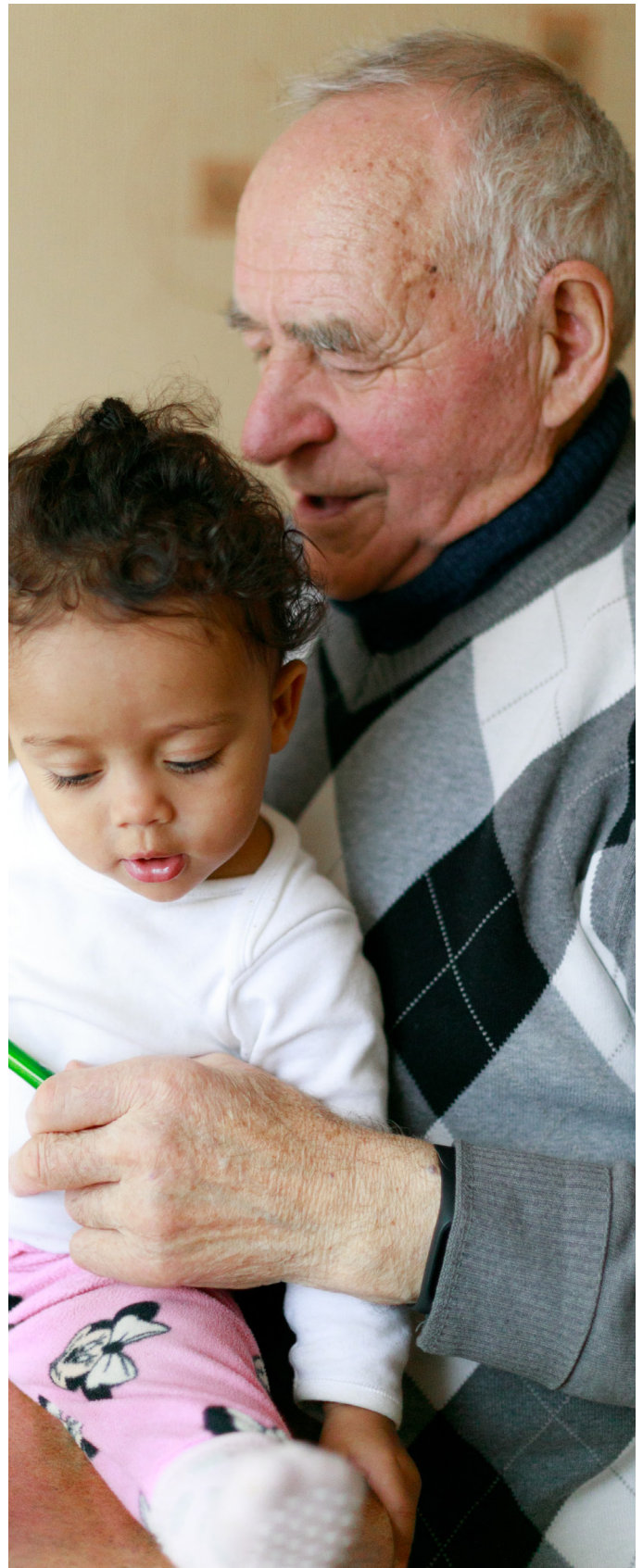
1. What are things that you often wish went more easily or caused less stress to you or your loved one?
2. What do you wish was available to you to support you in your role as caregiver?

Secondary questions accompanied the discussion of the two above questions.

Characteristics of the Community

The below data, from Census Reporter (2019) and Data USA (2018), captures the characteristics of the three counties within the Southern Tier that are addressed in this report:

- Chautauqua County:
 - Population: 126,903; Median age of 44.6
 - 21% of residents are 65+ with 15% (19,035) of residents 70+ years old, the typical demographic for those receiving care
 - 94.5% of residents have health coverage
 - 22.3% Medicaid, 14.4% Medicare
 - Average commute: 17.3 minutes
 - 80.9% drive alone, 4.35% walk, 14.75% use other methods
- Cattaraugus County
 - Population: 76,117; Median age of 42.5
 - 20% of residents are 65+ with 13% (9,895) of residents 70+ years old, the typical demographic for those receiving care
 - 93% of residents have health coverage
 - 20.1% Medicaid, 13% Medicare
 - Average commute: 20.9 minutes
 - 82.9% drive alone, 4.36% walk, 12.74% use other methods
- Allegany County
 - Population: 46,688; Median age of 39.1
 - 18% of residents are 65+ with 12% (9,338) of residents 70+ years old, the typical demographic for those receiving care
 - 93.1% of residents have health coverage
 - 18.8% Medicaid, 13.1% Medicare
 - Average commute: 21 minutes
 - 75.6% drive alone, 11.6% walk, 12.8% use other methods





Findings from Community Study

Through the focus groups, interviews, and surveys, there were common characteristics of caregivers and their scenarios. We provide a description to help illustrate the needs.

The assessment also highlighted the most significant needs. And the community characteristics also contribute to caregiver barriers.

Description of Caregivers

Obviously, each caregiver and caregiver situation is unique, but there are some characteristics that are found more often than others. We include the following description and composite scenarios to portray typical caregiver situations:

Typical Caregiver Descriptor

The caregiver is typically female, over the age of 45, caring for an aging parent, who is over the age of 75. Many of those parents have a disability or a chronic health condition. Many are experiencing some form of dementia. It is not unusual for the caregiver to be caring for more than one parent or supporting a primary caregiver as well as the person needing care (for example in the case of two living parents where one parent is in need of significant care and the other parent is the primary caregiver). Most are providing care either 4 – 8 hours a week or over 30 hours a week (often depending on whether they are residing with the parent). Many of these caregivers also have their own families and are trying to balance parenting their own children while also providing caregiving to a parent.

Most are frustrated, anxious, and stressed. Many were not expecting to be caregivers. They are often feeling lost and not knowing what to do for their loved one. When they have been at it a while, they yearn for a break.

Most are open to support and services but find the systems to be complex and they are already crunched for time. The process of being able to determine what help is available and how to access that help is in itself a barrier.

Typical Scenarios

These scenarios all include aspects of the real life stories shared with us during the assessment process but do not include real names or complete descriptions to protect anonymity of those involved.

Stacy is a single parent of one and works full time. She has one unreliable sibling that lives out of town. Stacy's Mom just had a heart attack and is in the ICU. Stacy is suddenly faced with knowing she will become a caregiver for her mother. Stacy has no idea what to do and how this is going to impact her life ... will her mother need to come stay



with her, will she need to stay with her mother, does she need to take time off of work, how will she care for her daughter and mother, what medical supplies might be needed, are there any services available, what will be the financial impact, where are her mother's bills and paperwork, does she have a will? Stacy has so many questions and she is not sure where to turn for help, if there is even help available. She feels lost and is so worried about her Mom.

Kathy is married with two small children and is currently a caregiver for both her infant daughter who has been in and out of the hospital multiple times due to a medical condition as well as her mother who has MS. She spends a lot of time going back and forth to the hospital and doctor appointments. She used to call her mother daily and visit occasionally. But recently things have gotten worse and she needs to stop daily to check on her. She loves her mother and values the time she spends with her, but it has put an extra stress on her given her daughter's needs as well. Needless to say, she is exhausted and has not spent any alone time with her husband in months. She has tried to find someone to lighten her load and stop in to see her mother daily, or even a few times a week, but has been unable to find anyone due to the shortage in health aides.

Nancy is married and the mother to two young teenagers. She works full time in a healthcare setting. Nancy's parents live about 25 minutes from her in their own home. Nancy's Mom is diabetic but had been getting along generally well. Her Mom has been working in a local grocery store and her Dad is retired. A couple of months ago Nancy's Dad had a stroke resulting in some paralysis and difficulty in speaking. It also seems to have shifted his generally jovial personality to one of anger and impatience. Nancy's Mom has needed to take a leave of absence

from her job, which she loved. The stress of the situation has led to some difficulties with managing her diabetes. Nancy is trying to help her Mom and Dad. She has started spending much of the weekend at their house so that her Mom can pick up some shifts at work. She is noticing that the house, usually clean and organized, is in disarray and dirty. Her Dad is very demanding but noncompliant when it comes to the recommended therapies he is asked to do at home. Nancy used to spend the weekends taking care of her own errands, spending some time with her children, and relaxing to prepare for the week of work. Nancy is worried about how to move forward. She is worried about the impact on her family, how to help her Mom manage with all the new concerns, and help her Dad move past his anger.

Key Learning: Despite the descriptions above, many people expressed the gift that they found in caregiving. Many felt grateful that they had the opportunity to provide care for their parents/loved ones. To capture some of those sentiments, we summarized their thoughts and included as Appendix F.

Gaps and Most Significant Areas of Need

The combination of the community survey, interviews, and focus groups highlighted three main gaps:

1. Caregivers lack knowledge of available supports and services
2. The systems of support are complex
3. Caregivers need direct help

We will also discuss some other characteristics of the community that contribute to the difficulty in supporting caregivers.



Caregivers Lack Knowledge of Available Supports and Services

Many caregivers are suddenly thrust into the role of caring for a loved one and few families have done any prior planning about how to address such a situation. In the families that we spoke to, all agreed that knowing more in advance would have been helpful, but few felt that they would have engaged in that planning even if they knew that it was available.

Sudden medical events (a stroke or a fall), behaviors that are new (leaving on the stove, aggression), or a noticeable change (time between visits reveals a deterioration in cognitive or physical abilities) create an immediate need and little understanding of where to start.

Those who felt they were most successful were those who had personal relationships with people “in the know” who could guide them. When asked in the survey, “If you have not received any help for caring for your loved one, would you consider getting help?”, 8.06% said that they have considered it, 19.35% said

that they have not considered it and 22.58% indicated that they hadn’t realized help was available. The focus groups revealed that they had little awareness that any services were available. Others didn’t know where to start to find them or even understand what they could be searching for. A focus group participant helped illustrate this: “People don’t reach out for help or know what is available. They are unaware they qualify for specific services as a caregiver.”

The number of views on the STHCS website which shares resources for the three counties served is about 1300 views per year. It was discovered that the landing page was being bypassed in many of these visits, and it was the landing page that invited direct contact with the Navigator. The consultants recommended that this invitation be more prominently placed within the website.

The Caregiver Navigator Project has been building its presence on social media resulting in 20,000 views on Facebook in 2020, with approximately 3/4 of those hits being related to paid boosts to promote the caregiver survey.

Key Learning: In the focus groups, it was evident the degree to which the participants looked to each other for reassurance and information. Despite the focus of the gathering not being a “support group,” the women almost immediately started operating as such.

Key Learning: These consultants have worked in other rural communities with similar challenges. Programs often exist in a community but are not well known or accessed. Given that the Caregiver Navigation Project was designed to support caregivers, the STHCS would like to see more “hits” on their resource pages. Additionally, there are very few calls made to the Caregiver Navigator. Later in this report, there is a recommendation related to marketing, and this observation is the major reason for it.

The Systems of Support are Complex

Even when caregivers are successful in identifying the various agencies and organizations that may be able to support them, they find the systems extremely complex and frustrating.

This complexity was discussed by the professionals we interviewed as well as the caregivers themselves. Each program or service has a unique set of eligibility requirements, often financial, that exclude those supports from some families or require a vigorous application process. When excluded, it is often unclear if an alternative resource is available to a family.

The following quotes from focus group participants were representative of the discussions.

- “If the system worked the way it is designed to, it would be wonderful.”
- “There is a lack of clarity of services and a lot of expenses to provide care. The system is designed to provide care, but it is complicated.”

The families are already overwhelmed with time-draining care and the energy needed to maneuver through complex systems, extensive applications, searching for information from their parents (who may not be capable of helping) often lead to them delaying or abandoning their efforts to secure help.

They usually discover along the way, or after the fact, that they did not take advantage of the many benefits available due to the system complexity.

Key Learning: Because of COVID-19, all interviews and focus groups were conducted via Zoom. Under normal circumstances several if not all of these interactions would have been done in person. However, it became apparent that using technology was a positive factor for several of the focus group participants. They would NOT have agreed to participate in the



focus group if it had been in-person. Barriers of time, transportation, childcare, or elder care would have been too significant. By holding the session over Zoom, they felt like they could manage it.

Caregivers Need Direct Help

One of the most needed forms of assistance for caregivers is direct help for the parent/loved one. In the community survey and focus groups, the need for direct help was identified as a need more than anything else.

The following comments from participants in the survey and focus groups illustrate the need for direct care:

- “My mother needs me to visit her every day -- while it’s not much, it takes a small toll on my sanity. I wish that someone could stop in and visit with her once/twice a week.” (Survey Respondent)
- “I wish for someone that could help with basic tasks or just sit with my parent so that I could get a moment to myself.” (Survey Respondent)
- “Just having another person for the doctor’s appointments. It was hard to get out of work.” (Focus Group Participant)
- “I wish for someone to visit with our loved ones .. they are lonely and isolated. It would alleviate stress knowing someone was going in to take care of them.” (Focus Group Participant)

The type of direct care depends on the situation, but the chart below speaks to the work that the caregivers are doing most often and would be candidates for someone supporting through direct care.

Which of the following ways do you care for your loved one? (36 survey responses)

ACTIVITY	# Responses	%
Take to Dr. appointments/manage Dr. appointments	33	91.7%
Grocery shop	31	86.1%
Transportation	30	83.3%
Cleaning and taking care of the house or property	29	80.6%
Emotional support	29	80.6%
Prep or provide meals	27	75.0%
Make phone calls on their behalf	24	66.7%
Give medications	21	58.3%
Pay their bills	19	52.8%
Socialization	18	50.0%
Lifting or moving	16	44.4%
Coordinate care in the home/arranging services	14	38.9%
Faith support	13	36.1%
Provide financial support	13	36.1%
Bathing	12	33.3%
Dressing	11	30.6%

Despite it being the most significant need, there is a shortage of qualified home health aides. This fact was supported by survey participants and the professionals that we interviewed who spoke of the lack of home health aides in the communities. (This is discussed in more detail below.)

The following quotes support the concern for the lack of staff to provide direct care:

- “It was difficult to find direct care workers, but it was even more difficult to use services such as Will Care or Health Department staff who could not be scheduled consistently for specific hours. We had doctor’s orders for specific dressing changes and other needs to be addressed, but the local agencies struggled with finding adequate staff and coverage hours to meet our needs.” (Survey Respondent)

- “A barrier to getting help is that some agencies do not have enough aides.” (Interviewee)

Some of the direct care needs require professionals to do these tasks while others could be provided by volunteers. But there is not a robust volunteer network that can compensate for the lack of paid supports. As stated by one of the focus group participants, “Finding volunteer programs and coordinating it is something we don’t have.”

Financial barriers are also an important barrier. Even if direct help was available, many families do not qualify for financial help and do not feel that they have the financial resources to pay for it themselves. In some cases, depending on the need, there are county programs that work on a sliding scale, but it is usually dependent on what specific



program the individual needs. And this adds to the complexity of figuring out what is available.

Key Learning: A primary caregiver’s family in many cases is also a source of stress. Some caregivers are “only children” and have no siblings to rely on to provide direct care supports, and so all the caregiving falls on them. In other cases, siblings second guess and interfere with the caregiving of the primary caregiver. They are often out of town and either from a distance, or from whirlwind visits, play havoc with the decisions that were already made. These family disagreements can often interfere in decision making or consistency of care.

Key Learning: The need for self-care was expressed directly and indirectly by those engaged. For example, one focus group member said “We cannot take care of other people if we cannot take care of our own needs. I received a massage as a gift, and it was one of the best stress relievers. We are in survival mode ... you cannot pour from an empty container.” Having home health aides available is the biggest way to relieve some of the stress on the caregivers.

Community Characteristics/ Gaps Impacting Caregiving

The three counties served by Southern Tier Health Care System are characterized by conditions that also contribute to these gaps impacting caregivers:

1. Digital Divide
2. Transportation/Distance to Services
3. Medical Equipment
4. Home Health Aides

Digital Divide

Options for telemedicine and online education are limited in Allegany, Cattaraugus, and Chautauqua counties as there are many gaps in internet access. Additionally, the internet is the primary preferred source for searching for information.

The region is characteristic of typical rural communities that suffer from significant gaps in internet access. Even where there is access, reliability is often a concern. According to the US Census Quick Facts, those with broadband internet access for each county are: Chautauqua 76.2%, Cattaraugus 71.7%

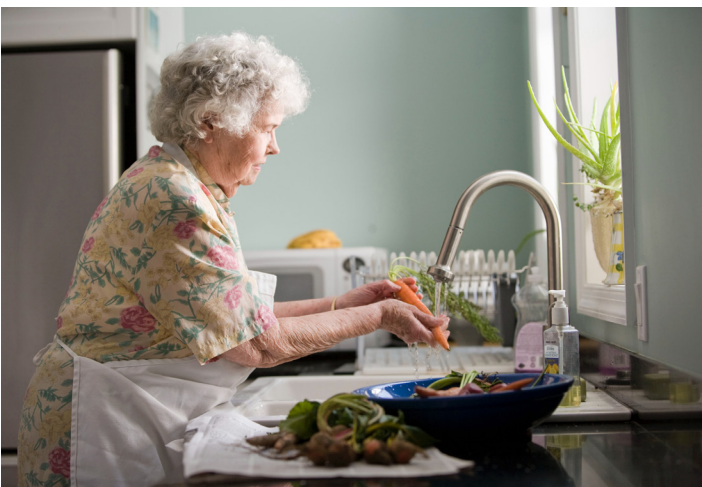
and Allegany 75.1%. However, this is for towns and cities with a population of 5,000 or more which excludes large expanses of the Southern Tier's very rural counties. The ability to compensate for lack of internet by going to places of businesses for Wi-Fi does not work well when the activity is doctor appointments, education sessions, or support groups.

Telemedicine and teletherapy have been important accommodations made during COVID-19 and would generally be beneficial to those who struggle with distance to their medical professionals, have disabilities, or lack transportation.

According to "HealthCareITNews" (August 2020), nearly 80% of cardiology, gastroenterology, pulmonology and respiratory physicians polled for a new survey said their use of virtual care technology has increased. That reporting matches the results of a national telehealth tracker during COVID-19. It found a national increase of 4,347% in telehealth claim lines.

These increases are not necessarily going to be sustained as the current use of telemed rely on a waiver of existing rules which may not be made permanent.

But even if made permanent, the lack of internet access in the Southern Tier would reduce the benefits of this policy change. Participating in telemed with both video and



audio is limited when internet access is poor.

Participation in online educational sessions or support groups is a significant help for caregivers with transportation, childcare, or time constraints. As illustrated by one of the focus group participants, "I would never have considered participating in this focus group today if it was in person."

Options such as online focus groups (or more importantly, education or support) are removed for people with no internet access.

The primary resource for finding information about caregiving options is the internet. Our survey showed that 27 of the 35 (60%) respondents to this question indicated they search on-line for information. The professionals that we spoke to also said that most people they serve find out about them through online formats such as their website or social media. For those dealing with internet gaps or reliability issues, their access to information in this preferred format is much more challenging.

Transportation/Distance to Services

Like most rural communities, the Southern Tier has limited bus routes, limited times of operation, and limited medical services.

Transportation within the counties is limited. The bus routes available to residents are not extensive and many communities do not have busses as an option. This lack of transportation can be a barrier for family members getting to their aging parents to provide care or to transport their parents to needed medical appointments.

MAS (a Medicaid transportation service) is available to those on Medicaid after they have pre-qualified. This service is helpful to some with financial barriers but leaves those above the Medicaid eligibility requirements with less options.

Many of the families that we spoke to in the focus groups needed to travel to Buffalo for medical appointments because local opportunities are limited. Even for those with transportation, there were reported cost barriers (for the transportation itself or needing to take time off of work) and time considerations.

The topic of transportation was initiated by participants in focus groups and interviews:

- “Transportation is a huge barrier. Being in a rural area, it is harder to coordinate given only one bus system.” (Interviewee)
- “I wish for more and better transportation opportunities.” (Focus Group Participant)
- “Transfer from one hospital to another was paid for in full, but I can’t get reimbursed for my mileage.” (Focus Group Participant)
- “Reimbursement would be helpful for transportation.” (Focus Group Participant)

Medical Equipment

There is a medical equipment lending program available in the three counties, however, there is a lack of awareness of these programs. Therefore, caregivers indicated the need to go to Buffalo to obtain medical equipment given the perceived lack of local options.

There is a listing of lending programs in Appendix B.

Home Health Aides

While already discussed above, the lack of home health aides is more complicated than just numbers. Survey respondents who have used home health aides spoke of inconsistency in care and concerns about level of care. “Continuity of care is very important. If the caregiver needs to train each worker, often it is just easier to do the work” said a survey respondent.

Professionals spoke of the difficulty in finding aides willing to go to the remote areas of the counties. Many agencies had money allocated for hiring aides but could not fill those positions as there were not sufficient applicants. “Workforce is the biggest problem. Funding is available to hire and place aides but there aren’t enough qualified people applying” said one of the professionals in the field who was interviewed.

Because of low wages and competition from other sectors, 17 percent of home health aide jobs across the state are unfilled, according to a Home Care Association (HCA) of New York report released in 2020. The result is that, according to HCA’s report, 24 percent of people in need of home health aides across the state can’t access them, and another 14.8 percent experience delays in service.

According to the newly released Genworth cost of care survey, the cost of homemaking services, such as cooking and cleaning, increased by 7.14 percent over the past year. The cost of home health aides, who provide personal assistance with activities such as bathing, dressing and eating, grew by 4.55 percent. The cost of adult day programs, a valuable service for both those living at home and their families, rose by more than 4 percent. For comparison, overall price inflation in the U.S. grew by just 1.7 percent over the past 12 months.

As a result of these steep increases, which have persisted over the past several years, home care is becoming less affordable for many families. Genworth estimates that the annual cost of a full-time home health aide now averages \$52,624, exceeding the average cost of an assisted living facility.



Recommendations

Goals and Actions

This plan was developed through a process of robust stakeholder engagement involving clients, providers, referral agencies, and the community and confirmed the value of the design process.

Based on the findings from the assessment as well as the characteristics of the community, we recommend that the Southern Tier Health Care System secure funding to maintain their full-time Navigator position to include a focus on the three related strategic approaches to the enhancement of Caregivers:

1. Create a robust menu for Caregivers to access.
2. Improve client access to trained caregivers.
3. Improve access to telehealth/education for caregivers.

For each of these focus areas, we provide a description and goals for the specific strategies below.

Appendix A is a chart highlighting the three strategic approaches and the main goals for each.

Maintain Full-Time Caregiver Navigator Position

STHCS moved from a part-time Caregiver Navigator position to a full-time position in June 2020, funded by the Ralph C. Wilson, Jr. foundation, with funding to end in May 2022.

As the Community Study suggests, there are significant needs in the community which are not yet being addressed. In addition to the on-going need in the community for connecting caregivers to services, there is also a substantial need to make changes within the community to better address the needs of caregivers and those they care for. This full-time Navigator position's primary activity is to support caregivers in identifying appropriate services and break down barriers of complexity. But it is just as important to work within the systems to address caregiver needs.

Create a Robust Menu for Caregivers to Access

Description

Most caregivers are not accessing services until there is an event that necessitates them. The "Navigator" is the connector between the caregiver and the network of supports and services that they may be able to utilize. The Navigator would have the deep knowledge of what services and programs are available and is able to guide frustrated and overwhelmed caregivers to the appropriate resources and navigate them through a very complex system.

The Navigator's success in helping a family is impacted by whether or not the appropriate supports are available. Through the creation of or facilitation of new programs and tools, the STHCS can help to reduce the gaps that exist in the community.

Through their collaborative partnerships, STHCS can be a catalyst for new programs and tools.

Time is also a consideration for caregivers as they are trying to navigate complicated lives that often includes working full time, raising children, and caring for an aging parent. A conversation which can help provide targeted next steps to obtain support and services would be of great value to caregivers.

There are good resources in the community now, but the community is not adequately aware of them. "Build it and they will come" is a phrase only good for the movies. STHCS is a primary resource and can enhance that role, but being a resource is only helpful if the community knows about it. STHCS needs to expand its community outreach and promote its Navigator services and tools so that the community knows who they are and they can ultimately better support caregivers.

This outreach requires financial resources and expertise to build a marketing and outreach strategy to reach the current community members in need of support as well as those who are likely to need it in the near future.

Goals

- Enhance Navigator to describe and distinguish caregiver services within the Southern Tier.
 - Determine organizations with services for caregivers and their loved ones.
 - Form connections with organizations to form partnerships for referrals and to stay up to date on the newest programs.
 - Work with hospital discharge planners.
 - Develop a “map” of services to guide supports within the Southern Tier.
 - Gather requirements and eligibility for programs and services along with any referral forms/outreach materials.
 - Develop a marketing strategy to promote Navigator services and tools. This should include providers, caregivers, and patients.
- Develop a website with tools and chat options to engage people.
 - Conduct research within the community to assess if this resource already exists.
 - Determine the scope of the resources that will be present on the web page (older caregivers, caregivers of children, etc.).
 - If determined that it is needed, secure funding.
 - Once funding is secured, contract with a professional web development company to put together search engine-like tool and chat features.
 - Build on current website design, adding resources as they are found.
- Design and source on-line support groups and educational opportunities.
 - Partner with local organizations to assist in marketing and facilitation of current groups.
 - Determine gaps in support groups, including location, stigma, poor advertising.
 - Determine topics of interest in areas of need for caregivers.
 - Identify local experts that can partner on educational programming.
 - o Create a video library for caregivers and providers to access on-demand.
- Develop a marketing strategy to promote Navigator services and tools.
 - Design a logo to brand the program.
 - Develop downloadable or printable “guides” for caregivers and providers to access anytime.
 - Develop and implement a strategy for reaching people without internet.

Appendix C, D, and E provide recommended tools and education sessions derived from the community assessment process.



Improve Client Access to Trained Caregivers (professional and family caregivers)

Description

There are needs within the community that are not being adequately addressed. According to the survey and the interviews, the most pressing needs caregivers have is for direct help. This includes help in the form of bathing, dressing, cleaning, meal preparation, transportation, grocery shopping, and socialization for the person they care for. Some of these needs require professionals to do these tasks while others could be provided by volunteers. A barrier to access to services include a shortage of staff and financial burdens. But other broader needs are also important in the consideration of what is needed for caregivers and the people they serve. These include:

- A shortage of quality home health aides and similar supports.
- The need for training for home health aides and similar supports to ensure consistency of care and a supportive/caring approach.
- Services for people with too much money to qualify for services, but not enough to self-pay.

- Transportation and reimbursement for transportation, especially when many medical appointments are taking place far away (such as Buffalo).
- Reducing the complexity in the systems providing support.
- The need for awareness of medical equipment available in the community.

Goals

- Develop the case for the need for training.
 - Survey existing home health aide organizations to determine gaps in employment.
 - Conduct assessment with caregivers and care recipients to understand and focus on caregivers needs using standardized assessments.
 - Show that with proper training and support, caregivers are more likely to be able to fulfill these responsibilities and keep their loved ones from having to return to the hospital.
- Develop a recruitment strategy for home health aides to address the shortage in the community.



- Partner with local organizations to create job placement after training completion.
- Determine why people are not going into home health care employment (i.e., training requirements).
- Develop career ladder for home health-type jobs.
- Secure funding for training certified home health aides and non-certified caregivers.
 - Identify leaders who will be champions and support the program with resources, vision, enthusiasm, and commitment.
 - Identify community partners to support the program.
 - Develop a training program that funders will support.
- Develop a timeline for home health aide training and caregiver training programs.
 - Determine training requirements for various levels.
 - Develop the soft skills needed to ensure they can work independently, without direct ongoing supervision, and the ability to work well within a team.

Improve Access to Telehealth/Education for Caregivers

Description

The Southern Tier Health Care System can be a convenor of agencies/thought leaders on these issues or represent the needs in legislative sessions. Some of what is needed for caregivers and the people they care for, especially for older adults who do not have family members to advocate on their behalf, are actual changes in the systems that make decisions on their care and deliver it.

Goals

- Design and promote advocacy for telemed waiver to be made permanent.
 - Determine usability issues caregivers and providers are having with telemed.
- Develop best practices for telemed for the community and providers.
- Produce tutorials to help educate community and providers on best practices.
 - Provide both formal and informal education for health care providers and caregivers.
 - Improve the health, well-being, and quality of life of caregivers and care recipients.
 - Reduce hospital re-admissions.
- Work to provide telemed access in communities where internet resources are scarce.
 - Improve video teleconference capacity using the most flexible approach to ensure access.
 - Identify champions who will support the program with resources and spread positive information about the work.





Conclusion

The STHCS has a strong commitment to the caregivers of the Southern Tier. Their desire to reduce the burden on families led to a community assessment and their recommendations responsive to the defined needs and barriers.

The key gaps identified are:

1. Caregivers lack knowledge of available supports and services.
2. Caregivers need direct help.
3. Digital divide.

The gaps will be addressed by implementing the goals of the three key strategic priorities:

1. Create a robust menu for Caregivers to access.
2. Improve client access to trained caregivers.
3. Improve access to telehealth/education for caregivers.

STHCS is hopeful that other community stakeholders and funders will partner with them to improve the caregiving experience and the outcomes for older adults.

APPENDIX A:

Overview of Recommendations

Southern Tier Health Care System Caregiver Navigation Project

Overview of strategic approaches and main goals to address the growing needs of caregivers in the Southern Tier counties.

Supporting details outlined in full report.

Full-Time Caregiver Navigator Position

Create a Robust Menu for Caregivers to Access

- Enhance Navigator to describe and distinguish caregiver services within the Southern Tier.
- Develop a website with tools and chat options to engage people.
- Design and source on-line support groups and educational opportunities.
- Develop a marketing strategy to promote Navigator services and tools.

Improve Client Access to Trained Caregivers (professional and family caregivers)

- Develop the case for the need for training.
- Develop a recruitment strategy for home health aides to address the shortage in the community.
- Secure funding for training certified home health aides and non-certified caregivers.
- Develop a timeline for home health aide training and caregiver training programs.

Improve Access to Telehealth/Education for Caregivers

- Design and promote advocacy for telemed waiver to be made permanent.
- Develop best practices for telemed for the community and providers.
- Work to provide telemed access in communities where internet resources are scarce.

APPENDIX B:

Medical Equipment Lenders

As noted in this report, there is lack of awareness of medical loan facilities; however, there are options available in each of the three counties.

Chautauqua County

- Chautauqua Loan Closet
Mayville Community Building
77 North Erie
Mayville, NY 14757
Phone: (716) 359-5880
- Chautauqua County Office for the Aging
7 N. Erie Street
Hall R. Clothier Building
Mayville NY 14757
Phone: (716) 753-4471

Allegany County

- Allegany County Office for the Aging
6085 State Rt. 19 North
Belmont, NY 14813
Phone: (585) 268-9390
- Bolivar American Legion
387 Main Street
Bolivar, NY 14715
Phone: (585) 928-2827

Cattaraugus County

- Olean Public Library Medical Loan Closet
134 N. 2nd Street
Olean, NY 14760
Phone: (716) 372-0200
- Cattaraugus County Department of Aging (assistance provided)
1 Leo Moss Drive, Suite 7610
Olean, NY 14760
Phone: (716) 373-8032

APPENDIX C:

Robust Website Enhancements – for Caregivers

The one-on-one support of a Navigator can be supplemented with enhancements to STHCS' current website. Based on the assessment process, tools and resources to address the following would be very beneficial and additional tools can be developed or provided based on Navigator discussions over time:

- **A Family Checklist:** A “to do list” of what to have prepared and available in case of emergency/ to prepare for caregiving (health care proxies, wills, banking account information, etc.). This tool might be an excellent way to introduce the community to STHCS services and help to prepare families for caregiving in advance of needing it.
- **Definition of Terms:** There are key documents often discussed, but many caregivers are confused on their differences and when each comes into play (for example: power of attorney, health care proxies, living wills). Additionally, this tool can share best practices for who should have them, when they should be available, and how to be prepared for emergencies.
- **Discussion Guide for Families:** Families themselves are complicated. When there are multiple siblings (or other involved family members), there is often conflict. This guide can offer questions to discuss about providing care, decision making, how to ask each other for help, and how to support from far away.
- **Key Questions to Ask Doctors:** A checklist of items to discuss with doctors, including around specific medical situations such as strokes, heart attacks, and dementia diagnosis, including what to plan for in terms of required care.
- **How to Successfully Have Telemedicine Appointments:** Helping families by addressing technology requirements, benefits, and mitigating negatives. Making the case that Telemedicine can reduce stress connected to time and finances is also key. Include process for ensuring that appointment will be covered by insurance.
- **Guidelines for Approaching Difficult Conversations:** This guide can include sentence starters and tips on specific topics such as driving, how a person has changed following a medical event, the need for time off from caregiving, estate planning, and bringing in help.
- **Options for Self-Care:** Most caregivers need to focus more on self-care and providing examples and “permission” would be helpful. Keeping some options short, simple, and less expensive will also be important.
- **Supporting the Primary Caregiver:** Many caregivers consider themselves to be “secondary” caregivers and they struggle with caring for the person with needs, but also providing support to the primary caregiver. Suggestions for this role would be helpful.

APPENDIX D: Robust Website Enhancements – for Providers

This process did not focus heavily on the role of medical providers, but there were several instances where there were examples of both positive and negative experiences with providers. Southern Tier Health Care System could consider a “Provider” section to their website which provides elements of professional development and tools regarding the provider’s role in supporting caregivers.

Based on the assessment, the following are areas of concern regarding information and resources coming from Providers:

- Information about a specific diagnosis and what that means for lives moving forward. For example, what to expect following a stroke.
- Where to go for help (such as referrals to the Southern Tier Health Care System website and Navigator).
- How and when to use Telemedicine – to create a comfort on the part of older adults on being treated in a new way.
- Involving/including the caregiver in the appointments and follow-up. Recognizing the need to make this suggestion, and the importance for the patient.

APPENDIX E: Robust Website Enhancements – Educational Opportunities

Educational Opportunities on the website would also be valuable. It can serve as a one-stop for training information (in person and online) available from all sources. Education is a very important support for families. Online learning, especially for busy people, can be an important tool. An easy-to-use menu and calendar to simplify the process for visitors to the website might require a different process for local agencies to share information (such as completing an online calendar).

Education can take various forms, all supported through the website:

- In-person
- Live online
- Recorded to be accessed at anytime

Some areas which seem to be desired by caregivers are:

- Stress Management
- Chronic Disease Management
- Legal Considerations
- Preparing in Advance
- Time Management

It also seems that a support group option would be beneficial for caregivers.

APPENDIX F:

The Gifts of Caregiving

Although taking care of loved ones is exhausting, frustrating, often depressing and often leaves the caregiver with little to give to their families or themselves, there is a bright spot to it all. After reflecting on it, the caregivers in the focus groups and on the survey shared the “gifts” they received from the past and present experiences that are offered below:

- “I took care of someone who died from cancer. This left me feeling guilty that it was taking time from my children. However, I discovered my children grew from the experience. They have a heightened level of compassion, care, and resiliency. My children became more loving through the experience.”
- “I love when I can get either parent to laugh – giving the ability to make them smile.”
- “Family is connecting more – aunts and uncles, cousins are connecting more than before.”
- “Really see faith in humanity restored since people are coming around and how they are giving of themselves for our loved one. It is very humbling, very restoring in my sense of humanity. There are so many things that are negative, but so much beauty has come out of caregiving.”
- “Through all of this, I talked to my only child and asked if he was paying attention to all that I am going through. My son said that he learned about it but would not be able to do what I was doing so would be sure to make good plans for me. It’s good to know your own capabilities and better to know that planning is important.”
- “We are helping to take care of parents who have done so much for us. One of our children has stepped up to help, learning lessons in compassion and resiliency.”
- “It’s not easy but is worth it to the individual.”
- “Just do what you can. You will have bad days, but the good ones will leave you with wonderful memories”.
- “I took to driving all night long with my dad in hopes he would go to sleep, given dementia and sundowners. Instead of sleeping, he talked and talked and talked about growing up, his time in the army and many memories from long ago. I will always cherish these long nights driving for hours on end.”
- “You will never regret it.”
- Advice from current/past caregivers to future caregivers
 - “Prepare in advance.”
 - “Be sure to always take care of yourself as well as your loved one.”
 - “Get help at the beginning. Don’t try to do it all yourself.”
 - “There is support out there.”
 - “You are not alone.”
 - “Keep positive, use humor, and laugh and smile.”
 - “I wouldn’t want it any other way with helping my mom but set schedules and take breaks.”



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