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Non-elderly adults on disability in the CF population

By Lea Nolan, Semret Seyoum, Julanne Wilson, and Marsha Regenstein
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Introduction

Cystic fibrosis is the most common, life-limiting, and fatal autosomal-recessive disease in the United States.¹ It is estimated to impact over 30,000 people in the US.^{2 3} Medical advances in coordinated clinical management, high-quality specialized care, and breakthrough therapies have produced impressive gains in life expectancy and quality of life for people with CF.^{4 5 6 7} CF was once a disease that primarily affected children, but now more than half the diagnosed population are adults.⁸

Despite these gains, people with CF still face considerable challenges. People with CF adhere to daily regimens of airway clearance, inhaled medications, oral supplements and vitamins, and exercise to improve lung function and improve energy while simultaneously juggling the demands of family, friends, school, and work. In addition, as adults with CF advance in years, they must contend with the progressive effects of the disease and the additional demands required to maintain health.

Many people with CF work full-time despite moderate disease severity.⁹ However, for a significant minority of adult CF patients, the disease's progressive nature and severity prove too difficult to address while simultaneously holding down a job. Several studies cite chronic, ill health as a primary factor that impacted career choice or led adults with CF to exit the workforce.^{10 11 12 13}

Some people who leave the workforce claim disability through the Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI) programs. SSDI and SSI are cash assistance programs rather than health insurance programs, although eligibility for one often leads to coverage by Medicare or Medicaid. SSDI is funded through payroll taxes and is designed to replace a portion of wages that cannot be earned because of the presence of a disability. SSDI is a need-based program, which means that the recipient's

assets are not factored into the formula for benefits. Applicants must be over 18 and under 65 to qualify. The amount of benefits is based on the age when disability occurred, the person's wages when working, and the number of earned work credits (which correspond to the number of quarters worked while paying Social Security taxes). Once determined to be disabled and eligible for SSDI cash benefits, the person with a disability faces a five-month waiting period before SSDI benefits begin. And, after receiving SSDI cash benefits for 24 months, a SSDI recipient will become eligible for Medicare. Thus, there is a precariously long waiting period from the time of disability designation to Medicare eligibility when the disabled person may be uninsured or underinsured. SSI is a strictly need-based program that factors in income and assets to determine eligibility. People qualify for SSI if they are determined to have a disability and less than \$2,000 in assets (or \$3,000 for a couple) and very low (or no) income. In addition to cash benefits, SSI recipients also receive Medicaid in their state and most qualify for Supplemental Nutrition Assistance Program (SNAP) benefits. SSI does not have a lengthy waiting period; benefits begin on the first of the month in which an applicant submits the application and are based on state/local rules.

Today, more than 20 million people in the US between the ages of 18 and 64 are considered disabled, or 10.3 percent of the population.¹⁴ In 2019, 17 percent of CF patients listed in the Cystic Fibrosis Foundation Patient Registry (CFFPR) report were categorized as disabled. An additional 7 percent were listed as unemployed.¹⁵

Disability payments are too low to cover the steep out-of-pocket expenses that people with CF face managing their disease. As a consequence, people with CF often struggle to afford necessary symptomatic treatments such as supplements, enzymes, and vitamins. Additionally, people with CF, and especially those on disability, require frequent medical intervention that can include hospitalization. Although SSDI includes Medicare coverage, the program requires substantial cost-sharing that leaves people with disabilities financially vulnerable with considerable medical bills. Additionally, the two-year qualifying period before Medicare coverage kicks in can leave people exposed to an even larger cost burden. SSI includes Medicaid which covers the cost of medical care but does not always provide coverage for the over-the-counter supplements, vitamins, and enzymes that people with CF need.

This issue brief focuses on adults aged 18-64 who have CF, and who are on disability or are considered to have a disability if they left the workforce due to the severity of their illness.¹⁶ (Throughout this issue brief we will refer to this population as non-elderly adults with CF on disability.) We recognize that many people with CF remain in their jobs despite moderate-to-severe illness. However, those on disability face significant constraints that leave them susceptible to financial deprivation. Thus, a special look at their circumstances is warranted.

Our analysis indicates that non-elderly adults with CF on disability are far more likely to have low incomes, not be employed for wages, experience financial burdens due

to high out-of-pocket medical costs, face unmet medical needs, accrue medical debt, and face other issues due to high medical costs such as food and housing insecurity, and bankruptcy. Further, we find that household income is the greatest indicator of financial insecurity among this population.

Our findings also highlight that common challenges associated with unmet medical need, medical debt, housing insecurity, and food insecurity are experienced more acutely among non-elderly adults with CF on disability.

Methods

Under contract from the Cystic Fibrosis Foundation, researchers from the Milken Institute School of Public Health at George Washington University developed an online survey, the 2019 Cystic Fibrosis Health Insurance Survey, to understand disability, coverage, access to care, and financial hardship among non-elderly adults, aged 18 to 64 years old, with CF in the U.S.¹⁷ Elderly adults, aged 65 and above, were excluded from this analysis as is customary when examining adults of working age.¹⁸ As part of the survey, non-elderly adults were asked questions related to disability payments, insurance type, and employment status to identify their disability status. Participants who responded that they are not currently working were asked a follow-up question to establish “What is the main reason you are not currently working for wages, salary, or contracted work?” Non-elderly adults with CF were determined to be on disability if they met one or more of the following criteria:

1. Receive disability payments
2. Are insured by Medicare, including individuals who are dually insured by Medicaid and Medicare
3. Are not currently working for wages, salary and contracted work, and the main reason is due to a disability or medical limitation

Survey participants were recruited with assistance from the CF Foundation. The Foundation shared the survey using social media and listservs, while also encouraging providers at the 133 accredited CF care centers across the United States to share the survey with their patients. All respondents represent a unique person with CF. The cross-sectional survey was fielded from July to December 2019. The final sample of non-elderly adults with CF includes 980 participants.

The sample was weighted to reflect the parameters of the CF Foundation’s 2019 Patient Registry Annual Data Report. The Registry is representative of the population of non-elderly adults in the U.S. who have CF and who seek care at an accredited care center.¹⁹ Survey weights were applied to adjust for non-responses by age group and insurance.²⁰

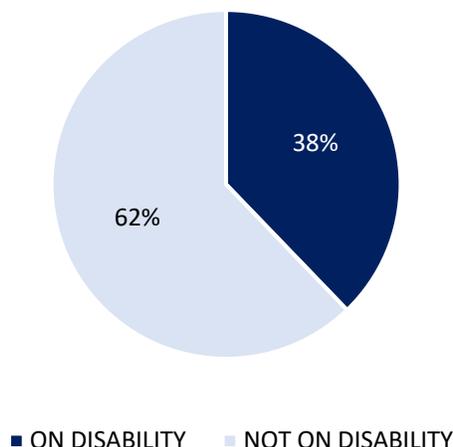
Descriptive and bivariate quantitative analyses were conducted to explore the subpopulation classified as on disability and make comparisons to those who are not on disability.

The 2019 Cystic Fibrosis Health Insurance Survey was conducted before the COVID-19 outbreak. Any additional challenges with COVID-19 regarding access to care and financial hardship will not be captured in this issue brief. Likewise, the survey was conducted before the release of the highly effective modulator therapy elexacaftor/tezacaftor/ivacaftor (Trikafta®). This brief does not capture the impact of Trikafta® on overall health status and well-being.

Identifying Disability

Data from the 2019 CF Health Insurance Survey indicate that more than one-third (38 percent) of non-elderly adults with CF in the U.S. are on disability (Figure 1).

FIGURE 1. DISABILITY STATUS OF NON-ELDERLY ADULTS WITH CF



As part of the survey, non-elderly adults were asked if they receive disability payments, their insurance type and employment status. Our survey sample reflects a higher prevalence of disability than that found in the CFFPR. Data from 2019 indicate that 22 percent of adults aged 30 to 35 years old, and 28 percent of those 40 to 64 years old receive Medicare coverage. Medicare beneficiaries under age 65 meet the federal criteria to claim disability status.²¹

Demographics

Characteristics such as gender, age, education, race, ethnicity, and employment vary between non-elderly adults on and not on disability.

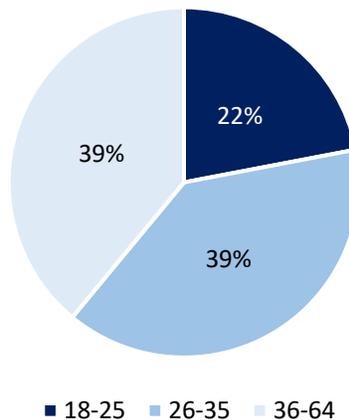
Age, Gender, Race/Ethnicity

In trends similar to the general population, women with CF were more likely than men to report being on disability, with 39 percent of females reporting being on disability compared to 32

percent of males.^{22 23} This is consistent with prior studies indicating gender-based differences in health and poorer health outcomes for female patients with CF.^{24 25 26}

Younger adults with CF are less likely to be on disability than their older counterparts. Just over a fifth (22%) of adults aged 18-25 years old reported being on disability. Older adults with CF were equally likely to report being on disability. Four in ten aged 26-35, and 39 percent of adults aged 36-64 reported being on disability.

FIGURE 2. AGE OF NON-ELDERLY ADULTS WITH CF ON DISABILITY



Note: There is a statistically significant association between age and disability among non-elderly adults with CF at a p-value <0.001.

Our survey sample roughly mirrors the overall racial and ethnic demographic makeup found in the CFFPR. Ninety-five percent of non-elderly adults with CF on disability in our sample are White, 3% are Black or African American, and 6% are Latino or Hispanic.²⁷ Non-Whites with CF have a disproportionately higher prevalence of being on disability than their White counterparts. Thirty-seven percent of White non-elderly adults reported being on disability, compared to nearly half of Black or African American non-elderly adults (48%).

When we examine differences by ethnicity, we find 40 percent of non-elderly Latino or Hispanic respondents reported being on disability, compared to 37 percent of non-Latino or Hispanic respondents. These findings must be interpreted with caution since the number of Black or African American and Latino or Hispanic respondents in the survey is small.²⁸ However, they are consistent with national data that demonstrate that the number of Latinos or Hispanics living with disabilities is increasing.²⁹ Of special concern are recent studies that show Latino or Hispanic patients with CF experience disparities in both pulmonary function and mortality compared with non-Latino or Hispanic white patients.^{30 31}

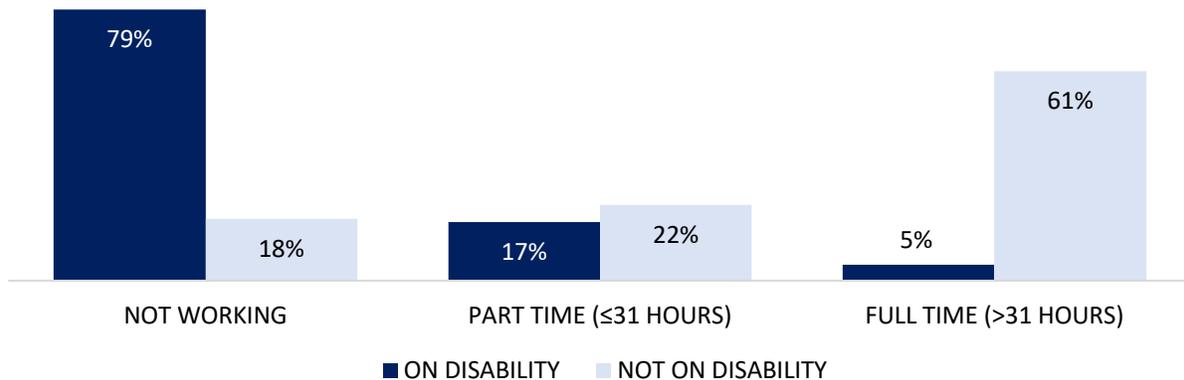
Employment

Non-elderly adults with CF on disability are far less likely to be employed than those who are not on disability. Our results show that non-elderly adults on disability are more than four times as likely to be unemployed than are their counterparts (79 percent versus 18 percent).

The prevalence of joblessness increases if a non-elderly adult with CF is on disability.

Similar trends persist when we examine our findings by employment status. Non-elderly adults with CF on disability are also less likely than those who are *not* on disability to work either full or part-time jobs. Among those non-elderly adults with CF on disability, 17 percent worked part-time and just 5 percent worked full-time (Figure 3).

FIGURE 3. EMPLOYMENT STATUS OF NON-ELDERLY ADULTS BY DISABILITY STATUS



Note: There is a statistically significant association between employment status and disability among non-elderly adults with CF at a p-value <0.001.

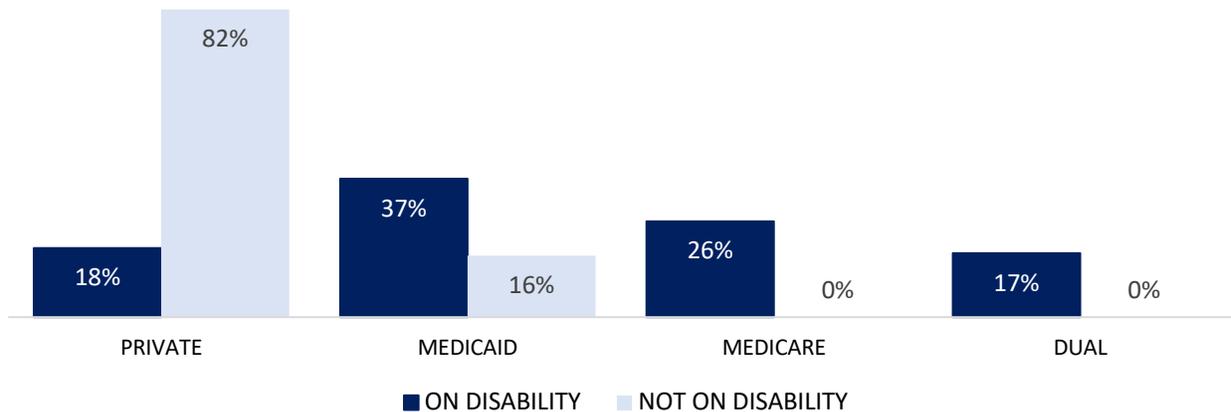
Employment is a key factor in the lives of people with disabilities. However, people with disabilities who receive public benefits such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are limited in how much they can earn from employment before benefits are reduced and still maintain those benefits. This can artificially suppress employment status or working hours for some people with disabilities. Programmatic inflexibility also makes it difficult to obtain short-term assistance when needed. For people with CF undergoing an acute exacerbation of their illness, a temporary exit from the workforce with full health care benefits and social supports could result in re-entry to the workforce with no penalty. Since household income is so strongly associated with receipt of benefits, more research needs to be done to understand the factors that influence the ability to work and move to disabled status.

Our survey did not include questions about the factors affecting whether people on disability worked full or part time jobs. Studies that examine the interplay between CF and the ability to work suggest a variety of factors contribute to a person’s ability to work on disability. While forced expiratory volume (FEV₁) played a role in some studies, others demonstrated that people with CF could maintain employment with significant lung damage. Therefore, disease severity alone is not a good predictor of employment outcomes. Other factors such as depression, frequency of hospital admission, education level, type of work, number of hours worked, and job counseling may be better indicators of whether a person with CF will obtain and maintain a job.^{32 33 34} Though not related specifically to disability status, people with CF are at additional risk of infection which limits the range of employment opportunities.

Insurance

The majority of non-elderly adults with CF on disability are covered by some form of public insurance. Of those respondents on disability, 37 percent are covered by Medicaid, 26 percent are covered by Medicare, and 17 percent are “dual eligible,” individuals covered by both Medicaid and Medicare. Only 18 percent of those on disability have private insurance (Figure 4).

FIGURE 4. INSURANCE TYPE OF NON-ELDERLY ADULTS WITH CF BY DISABILITY STATUS



Note: There is a statistically significant association between insurance and disability among non-elderly adults with CF at a p-value <0.001.

Many dual eligible individuals qualify for both SSDI and SSI because they meet the Social Security Administration’s (SSA) rigorous criteria for disability and have very low incomes. The SSA places strict limits on how much income people can earn and retain eligibility for these disability programs. People who qualify for SSI can earn about \$1,650 USD per month in wages and still qualify for benefits.^{35 36} Some people with CF who depend on these disability programs

may be able to work additional hours when their health permits; however, the earnings from these extra hours may put their disability status at risk.³⁷ While working additional hours would mitigate some of the challenges of paying for costly out-of-pocket therapies and supplements, people may not have the option of earning additional income for fear of losing their benefits.

People with disabilities are far more likely to be covered by publicly funded health programs than private health insurance.

Access and availability to health insurance is critical to people with disabilities, so much so it can impact decisions about important life events such as where to live and whether to get married. This holds true across the board for people with CF, though more so for the disabled group. More than a third of non-elderly adults on disability reported that insurance affected which state they wanted to live in, compared to a fourth that did not have a disability. This could be because some states have more generous supplemental SSI payments, and some do not provide a supplement at all.^{38 39 40} Health insurance affected decisions about marriage for 43 percent of non-elderly adults with CF on disability compared to 25 percent who are not on disability. Decisions regarding marriage are a concern for SSI beneficiaries because spousal income can be deemed part of the recipient's income and therefore affect the amount of the benefit.^{41 42} SSDI payments are not impacted by spousal income.

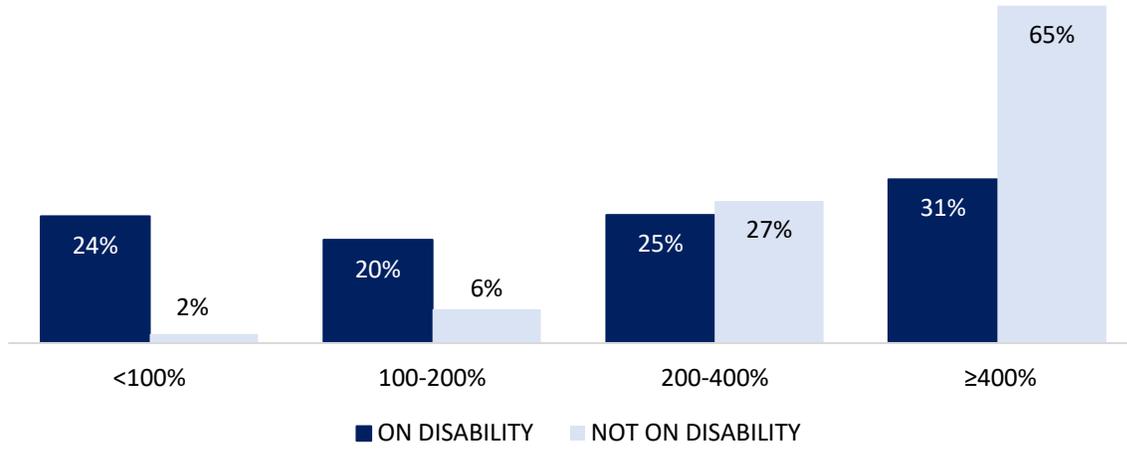
Income

Income plays an important role in one's ability to live independently. Disability has a significant impact on workers' income, economic circumstances, and their ability to purchase essentials like housing and food.⁴³

CF patients on disability are much more likely to have lower incomes than people with CF who are still able to work.

More than a fifth of survey respondents on disability had incomes below or equal to 100 percent of the 2019 Federal Poverty Level (FPL), compared to two percent of those who did not have a disability. Another one in five respondents on disability had an income between 100-200 percent FPL (Figure 5).

FIGURE 5. PERCENTAGE OF 2019 FEDERAL POVERTY LEVEL OF NON-ELDERLY ADULTS WITH CF BY DISABILITY STATUS



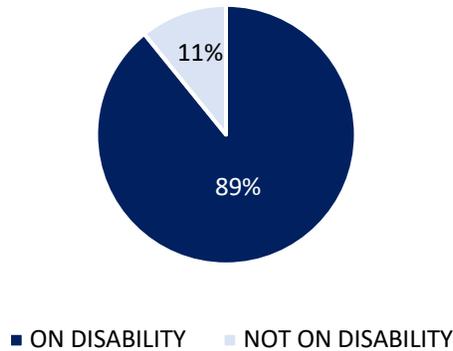
Note: There is a statistically significant association between poverty and disability among non-elderly adults with CF at a p-value <0.001. Percentage of FPL calculated using the poverty guidelines updated periodically in the Federal Register by the U.S. Department of Health and Human Services under the authority of 42 U.S.C. 9902(2).

Similarly, non-elderly adults with CF who are *not* on disability were more likely to have higher household incomes than those on disability. Non-elderly adults with CF who were able to work were more than twice as likely to have household incomes above or equal to 400 percent FLP than those on disability (65 percent versus 31 percent).

In general, it is important to stress that non-elderly adults with CF on disability have incomes that are fairly evenly spread across income categories. Our results show that three-fourths of respondents on disability do not live under the poverty level.

Our findings bring into stark relief that, while disability is not necessarily about poverty, for non-elderly respondents with CF, poverty *is* about disability. Within the lowest income category, there is a higher prevalence of non-elderly adults with CF on disability and a lower prevalence within the highest income category. Eighty-nine percent of non-elderly adults with CF living under the poverty level are on disability (Figure 6). Similarly, when we examine those with incomes equal to or higher than 400 percent of poverty, 77 percent are *not* on disability compared to 23 percent who are on disability.

FIGURE 6. NON-ELDERLY ADULTS WITH CF BELOW THE 2019 FEDERAL POVERTY LEVEL (<100% FPL) BY DISABILITY STATUS



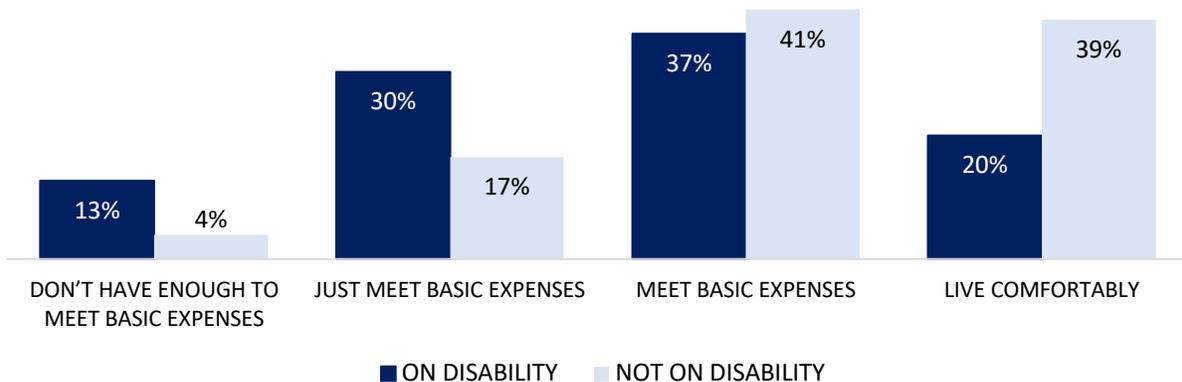
Note: There is a statistically significant association between poverty and disability among non-elderly adults with CF at a p-value <0.001.

Financial Burden

Household Finances

To estimate financial burden within households of non-elderly adults with CF on disability, we asked survey respondents to indicate which scenario best describes their household’s financial situation: whether they live comfortably, meet basic expenses with a little leftover for extras, just meet basic expenses, or don’t have enough to meet basic expenses (Figure 7). This question has been used in other national surveys to measure the financial status of those with medical bill problems.⁴⁴

FIGURE 7. HOUSEHOLD FINANCIAL SITUATION OF NON-ELDERLY ADULTS WITH CF BY DISABILITY STATUS



Note: There is a statistically significant association between household financial situation and disability among non-elderly adults with CF at a p-value <0.001.

In households with lower incomes there is a higher prevalence of non-elderly adults with CF on disability.

Financially strapped households are at great risk of not being able to provide for their daily and medical needs, much less devote funds to luxuries or long-term financial planning. A sizeable minority of non-elderly adults with CF on disability either do not have enough money to meet their basic expenses (13 percent), or just meet their basic needs (30 percent). Only one in five people with CF on disability reported that they have enough funds to live comfortably (20 percent). It should be noted that CF patients who live comfortably still face high out-of-pocket costs for co-pays, therapies, and supplements that are often not covered by insurance. Given that patients with CF are at risk for needing expensive acute or tertiary care, these costs can balloon and pose a serious hardship for patients and their families.

Unmet Medical Need

Out-of-pocket expenses are associated with increases in the likelihood of unmet medical need. Even people who pay relatively little out-of-pocket may still face some unmet medical need. Nonfinancial factors such as transportation, health literacy, cultural differences, and provider availability can play a role in reducing patients' access to needed health care services.⁴⁵ For example, the cost of transportation to obtain prescriptions may be high enough that it leads to delaying or skipping medications. For people with CF, over-the-counter non-prescription medications, supplements, and vitamins may not be covered by Medicare or state Medicaid programs therefore putting additional financial pressure on patients to purchase these products to fully meet their needs.

Non-elderly CF patients on disability reported equal or more unmet medical need than their counterparts.

Survey respondents were asked to provide information about their unmet medical need due to cost. Overall, two-thirds of non-elderly adults with CF on disability reported delaying care due to cost. This is nearly one-and-a-half times the rate of respondents who are *not* on disability (66 percent versus 43 percent).

FIGURE 8. UNMET MEDICAL NEED AMONG NON-ELDERLY ADULTS ON DISABILITY



*Note: * Denotes that there is a statistically significant association between unmet medical need and disability among non-elderly adults with CF at a p-value <0.05 ** Denotes a p-value <0.01 *** Denotes a p-value <0.001.*

Non-elderly CF patients are accustomed to delaying care due to cost; those on disability delay their care even more.

As demonstrated in Figure 8, 45 percent of non-elderly adults with CF on disability put off dental care, and four in ten reported delaying medications due to cost. A quarter of respondents on disability had tried to delay or shorten a hospitalization, while a fifth reported that they did not obtain a medical test or treatment that had been recommended by their physician due to cost (21 percent).

Non-elderly adult CF patients were asked if they delayed CF care center visits when they did not feel well because of cost. Underuse of care center visits associates with poorer health outcomes for people with CF.⁴⁶ As shown in Figure 8, 20 percent of people with CF on disability delayed a visit to their care center when they did not feel well, and 15 percent reported that they had skipped one CF care center visit.

Problems Paying for Medical Bills

In addition to the focus on unmet medical need, we also looked at the affordability of specific medical services. We worked with the CF Foundation to identify common prescription and over-the-counter medications and supplements, and services and treatments utilized by people who have CF. About 57 percent of people with CF on disability had problems affording these common CF medications and services/treatments.

Obtaining necessary care is hard for the CF population in general; it is particularly challenging for vulnerable CF patients on disability.

Table 1. Percentage of Non-elderly Adults With CF Who Had a Problem Paying for Medical Services and Treatments, by Disability Status		
	On Disability % (N=371)	Not on Disability % (N=610)
<i>Any problem paying for medical services and treatments ***</i>	57% (n=212)	42% (n=259)
Treatments		
CFTR modulators **	23% (n=57)	14% (n=54)
Chronic inhaled antibiotics **	26% (n=77)	17% (n=75)
Diabetes supplies *	22% (n=56)	14% (n=40)
GI therapies ***	22% (n=74)	12% (n=62)
Hypertonic saline *	16% (n=46)	11% (n=54)
Insulin	19% (n=43)	12% (n=31)
Home IV treatment for PEx **	28% (n=68)	16% (n=42)
Nebulizers or compressors (including replacement)	23% (n=76)	17% (n=96)
Pulmozyme *	22% (n=70)	16% (n=81)
Vitamins and supplements ***	32% (n=115)	15% (n=90)
Services		
CF routine visit *	21% (n=74)	15% (n=89)
CF sick visit *	17% (n=56)	12% (n=55)
Home health nursing services	19% (n=44)	14% (n=38)
Pulmonary function test ***	21% (n=74)	12% (n=68)
Seeing specialist during CF visit	21% (n=71)	16% (n=83)
Transplantation services and medications**	19% (n=33)	8% (n=13)
<i>Note: * Denotes that there is a statistically significant association between problems paying for medical services/treatments and disability among non-elderly adults with CF at a p-value <0.05 ** Denotes a p-value <0.01 *** Denotes a p-value <0.001.</i>		

Table 1 shows that between 16 and 32 percent of non-elderly adults with CF on disability have a problem affording certain medications or supplements. For each medication and supplement examined, CF patients on disability were more likely to report difficulty affording those goods than were their counterparts not on disability. Vitamins and supplements were most reported as difficult to afford (32 percent). Slightly more than a quarter of non-elderly CF patients on disability had challenges paying for chronic inhaled antibiotics; and 23 percent had trouble paying for CFTR modulators. Many non-elderly adults on disability take advantage of pharmacy assistance programs, for example, 65% report using HealthWell⁴⁷ and more than a third use patient assistance or copay assistance programs sponsored by drug companies to help offset costs (38 percent). But these programs are not sufficient to cover the full cost of prescription and non-prescription medications, especially among people who have very high medication

needs. In a previous issue brief, the authors also found that people with CF who had problems paying for CF care center visits and medications were more likely to delay or skip taking prescription medications.⁴⁸ There are many social factors at play that may contribute to this.

Failure to adhere to physician recommended pulmonary medication regimens is both risky and costly for people with CF since it is associated with poor health outcomes and higher acute health-care use.^{49 50}

Non-elderly adults with CF on disability also reported more difficulty affording treatments and services across the board than did their counterparts. Intravenous treatment at home for pulmonary exacerbations (PEX) was most often cited as challenging to afford by non-elderly adult CF patients on disability (28 percent). Respondents also had trouble paying for nebulizers or compressors, including replacements (23 percent), and diabetes supplies (22 percent). More than a fifth of respondents on disability reported difficulty affording aspects of their CF care. Twenty-one percent had trouble affording a CF routine visit, and an equal share expressed difficulty seeing a specialist during a CF visit. Poor adherence to medications has been linked to worse health outcomes including an increased number of PEX and baseline lung function.^{51 52}

While unmet need for all services and treatments was greater for the group on disability, it should be noted that those who are *not* on disability reported considerable unmet need for vital care as well, especially chronic inhaled antibiotics and nebulizers or compressors.

Household finances and the cost of medication, services and treatment have a clear impact on unmet medical need due to cost. When people with CF struggle to meet their basic expenses or have difficulty paying for medication or a treatment, they are more likely to compensate by taking less medicine, delaying filling a prescription, or skipping a needed service.

Financial Issues

People with CF who have disabilities don't just face medical hardships. Their medical conditions also impact their ability to pay for necessities, such as housing and food. More than eight in ten (86 percent) non-elderly adults with CF on disability reported having a financial burden that affected the quality of their lives. We examine some of these hardships in Table 2.

Table 2. Percentage of Non-elderly Adults With CF On Disability by Financial Issue	% (N=371)
Any Financial Burden ***	86% (n=318)
Debt	
Contacted by a collection agency ***	56% (n=180)
Borrowed money from friends or family ***	43% (n=140)
Filed for bankruptcy *	9% (n=29)
Increased credit card debt *	47% (n=167)
Took out another type of loan ***	19% (n=67)
Any Debt ***	74% (n=275)
Housing	
Forced to move or evicted ***	9% (n=29)
Had difficulty paying rent, mortgage, or utilities ***	37% (n=132)
Any Housing ***	38% (n=142)
Food Insecurity	
Had difficulty paying for food ***	32% (n=105)
Couldn't afford to eat balanced meals recommended by care team ***	33% (n=122)
Groceries didn't last and didn't have money to get more ***	33% (n=122)
Ate less than should because not enough money ***	26% (n=96)
Cut size or skipped meals because not enough money **	29% (n=105)
Hungry but didn't eat because not enough money ***	21% (n=76)
Used the Supplemental Nutrition Assistance Program (SNAP) ***	28% (n=102)
Went to a food bank ***	16% (n=58)
Turned to a place of worship for food ***	8% (n=28)
Any Food Insecurity ***	56% (n=209)
Savings	
Took money out of retirement, college, or long-term savings **	37% (n=133)
Used up all or most of savings **	44% (n=153)
Any Savings ***	55% (n=202)
<i>Note: * Denotes that there is a statistically significant association between financial burden and disability among non-elderly adults with CF at a p-value <0.05 ** Denotes a p-value <0.01 *** Denotes a p-value <0.001.</i>	

First, we surveyed a number of issues related to medical debt. Non-elderly adults with CF were asked if they have ever been contacted by a collection agency, borrowed money from friends or family, filed for bankruptcy, increased credit card debt, or took out another type of loan due to

their medical bills. A majority of non-elderly adults with CF on disability had been contacted by a collection agency (56 percent). Nearly half increased their credit card debt (47 percent), and 43 percent had borrowed money from friends or family. A significant minority took out another type of loan (19 percent) or filed for bankruptcy (9 percent).

Next, we examined the impact medical bills might have on CF patients' housing. More than a third of non-elderly adults on disability reported difficulty paying their mortgage or utilities due to their medical bills (37 percent); 9 percent were forced to move or were evicted.

Food insecurity is a serious concern for people with CF given their need for a high calorie, nutritious diet. We sought to understand the extent to which medical debt impacted respondents' access to food. Nearly 60 percent reported having difficulty affording food. Over one-quarter (28 percent) of non-elderly adults with CF on disability used the SNAP program. People on disabilities were overrepresented among the group who used SNAP benefits. Thirty-two percent of non-elderly adults with CF reported that they had difficulty paying for food. A third stated that they couldn't afford to eat balanced meals recommended by their care team. Similarly, a third of respondents stated that their groceries didn't last, and they didn't have enough money to purchase more. Many of these respondents turned to alternative sources for food. Sixteen percent reported going to a food bank, and 8 percent sought food at a place of worship. In a previous issue brief, we focused on food insecurity amongst the larger CF population. We found that 33% of individuals with CF, across all ages, have experienced food insecurity; and younger adults were most likely to experience food insecurity. Additionally, individuals or families with lower income had significantly higher odds of food insecurity.⁵³ Given our current focus on disability among non-elderly adults, it's understandable that a higher portion of our sample report food insecurity than the average person with CF, particularly when accounting for the similar associations between poverty and disability, and food insecurity and disability.

Some respondents on disability either cut back or went without food due to their debt. Twenty-nine percent cut the size of their meal or skipped it due to lack of funds; 26 percent ate less than they should because they couldn't afford it. Twenty-one percent stated they'd been hungry but didn't eat because they didn't have enough money. Our findings are consistent with a study that showed disability reduces workers' purchases on food and housing by an average 25 percent ten years after the onset of disability.⁵⁴

Non-elderly adults with CF on disability are more financially vulnerable than the general CF population, and more likely to face housing, food, and some debt-related challenges such as bankruptcy.

We sought to understand how some non-elderly adults with CF respond when faced with medical debt. We asked a series of questions to determine whether it was possible to identify additional funds either by liquidating assets or earning additional money. While non-elderly adults with CF on disability did report taking money out of retirement, college, or long-term

savings, they were less likely to do so than were those not on disability (45 percent versus 55 percent). Similarly, respondents on disability were less likely to use up most or all of their savings than respondents not on disability (43 percent versus 57 percent). This could be because CF patients on disability are less likely to have amassed savings due to the severity of their illness and lengthy absence from the workforce. We also asked respondents whether they had ever taken an extra job or worked more hours to earn money to pay their medical debt. Non-elderly adults with CF who are *not* on disability were far more likely to take on extra work than were respondents on disability (64 percent versus 36 percent). This may be because people on disability are not healthy enough to take an extra job or work more hours, or because they fear that additional earned income will threaten their SSI benefits.

Conclusion

All people with CF contend with the daily demands of their disease while maintaining the responsibilities of family, work, and school. With the help of advanced medicine and protocols for managing their condition, many adults with CF are able attend school or remain in the workforce despite moderate-to-severe illness. But for some non-elderly adults with CF, the disease's progression and severity leads them to make the difficult decision to leave school or the work force and file for disability. Our results show this sizable minority therefore becomes the most vulnerable of the vulnerable.

Data from the 2019 CF Health Insurance Survey indicate that more than a third of non-elderly (38 percent) of adults with CF in the U.S. are on disability.

Disability is seen across all non-elderly adults with CF but is less common among younger patients. Women with CF are more likely to be on disability, and a disproportionately higher proportion of racial and ethnic minorities are on disability than their White counterparts. Non-elderly adults with CF on disability are far less likely to be employed for wages; much more likely to receive Medicare and/or Medicaid than private insurance; and have lower household income than CF patients not on disability.

Without question, a lack of financial resources is the most significant factor impacting most risk factors we address in this issue brief, especially for non-elderly adults with CF on disability. Nevertheless, we add a cautionary note that focusing only on income can overlook pockets of need across all income categories.

Low household income and barriers to generating income through work appear to be the key indicators for financial burdens due to high out-of-pocket medical costs, unmet medical needs, problems paying for necessary services, medical debt, and other issues such as housing and food insecurity among non-elderly adults with CF on disability.

Twelve times as many non-elderly adult CF patients on disability have incomes below the poverty rate than patients not on disability (24 percent versus 2 percent). They are much more

likely to experience any delay in care than their counterparts (66 percent versus 43 percent), have higher out-of-pocket expenses, and are more likely to carry medical debt. Their financial vulnerability makes them especially susceptible to both food and housing insecurity.

It is troubling to see how financially perilous the economic picture is for many non-elderly adults with CF on disability, especially when they are also challenged with managing life-long chronic conditions. Career counseling should be provided to assist CF patients to better understand their employment options. Emphasis should be made on helping them stay in the workforce as long as possible. Expansions in programs like SNAP and new programs to address a growing epidemic of food and housing insecurity in the country should also be available for people with chronic conditions, and others who are resource constrained. To the extent possible, all payers should provide adequate coverage for all necessary CF therapies in the care regimen, including enzymes, supplements, and vitamins, especially for non-elderly adults on Medicare due to disability. Health costs that accrue to patients due to out-of-pocket requirements compete with the costs of basic needs of daily living, like food and shelter. This is especially true for people with CF who have disabilities and face a plethora of costs to maintain and manage their health. Medicare beneficiaries do not have annual out-of-pocket maximums and can face financial burdens due to medical bills and medication costs that build year after year. Non-elderly adult CF patients on disability are making decisions about whether to delay care; cut back or skip their medications and supplements, services, and treatments; get food or forgo necessary calories; in addition to many other decisions related to care management, given the resources available to them.

Effective and sustainable programs and policies that are robustly funded at the federal and state level are needed to reduce this gap between CF patients who have disabilities and supportive resources. Screening for patients with disabilities who have low incomes should be a routine part of care in order to identify those who have significant debt that could lead to lower medication and therapeutic adherence.

Note: This survey was conducted prior to the outbreak of COVID-19. To the extent that CF patients with disabilities face increased financial and coverage-related barriers due to circumstances related to COVID-19, the findings presented in this brief are likely to underestimate the circumstances within the CF population.

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Appendix

APPENDIX. General Characteristics of Non-elderly Adults With CF by Disability Status				
	On Disability		Not on Disability	
	%	N	%	N
Total	38%	371	62%	610
Gender *				
Male	32%	119	40%	243
Female	68%	248	59%	361
Age ***				
18-25	22%	80	36%	221
26-35	39%	146	36%	221
36+	39%	145	28%	168
Education (ages 26-64) ***				
High School Graduate/GED or less	15%	42	6%	23
Some college or 2-year degree	36%	106	24%	93
4-year college graduate	34%	100	36%	141
More than a 4-year college degree	15%	43	34%	133
Ethnicity				
Latino or Hispanic	6%	22	6%	34
Race				
White	95%	350	96%	585
Black or African American	3%	10	2%	11
Do you currently work for wages, salary, or contracted work? (18+) ***				
Yes	14%	77	82%	474
No	71%	282	18%	101
Poverty (%FPL) ***				
<100%	24%	90	2%	11
100-200%	20%	73	6%	39
200-400%	25%	91	27%	166
400%	31%	116	65%	394
Insurance Type ***				
Private	18%	67	82%	494
Medicaid	58%	136	16%	99
Medicare	83%	94	0%	0
Dual	100%	64	0%	0

Note: * Denotes that there is a statistically significant association between the demographic variable and disability among non-elderly adults with CF at a p-value <0.05 ** Denotes a p-value <0.01 *** Denotes a p-value <0.001.

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- ¹⁶ We note that there are 17 people who reported that they work full time and are also on disability, but our survey does not allow us to tease out discrepancies when people may be in the transition to disability. We include them in our sample of non-elderly adults on disability, even though our analysis doesn't allow us to verify the onset of symptoms that qualify them for disability or the timing of their transition to disability status.
- ¹⁷ The survey used previously validated questions from national surveys related to unmet medical need, coverage, access to care, and financial hardship. Some questions were modified to fit the CF population's experience, and developed new CF-specific questions about services, treatments, and supplies with input from CF Foundation staff and advisors. The survey also included questions on socio-demographic characteristics, general health, CF-related illness and challenges, insurance benefits and coverage, access to care, and costs of CF care.
- ¹⁸ Additionally, most elderly adults age into Medicare, which presents differences within the Medicare group based upon age. The subset of elderly adults (n=22) is not large enough to make informed comparisons. Given the data limitations and the focus on working age adults on disability, elderly adults were excluded from the analysis.
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- ²⁰ People with CF were categorized into three age groups- young adults 18-25 years old, and older adults 26-35 years, and 36+ and above. For insurance, we identified six unique categories- private, Medicaid, Medicare, Duals, other, and uninsured. To account for people with multiple insurance types we identified respondents as belonging to one insurance category, using the following decision criteria:

- Medicaid: Respondents whose coverage is Medicaid, CHIP, or a state program. The Medicaid category includes respondents with any of these programs or respondents with other sources of coverage in addition to Medicaid, CHIP or a state program, except for respondents with Medicare, who are otherwise categorized (see below).
- Medicare: Respondents whose coverage is Medicare. The Medicare category includes respondents with Medicare alone or with any additional sources of coverage, except for respondents with Medicaid.
- Duals: Respondents whose coverage includes Medicare and Medicaid. The Duals category includes respondents with Medicare and Medicaid only, or respondents with Medicare, Medicaid and additional sources of coverage.
- Private: Respondents whose coverage is private. The private category includes participants with any other additional sources of coverage, except for Medicaid and/or Medicare.
- Other: Respondents whose coverage is not private, Medicaid, Medicare, or uninsured.
Uninsured: Respondents who report they do not have insurance.

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