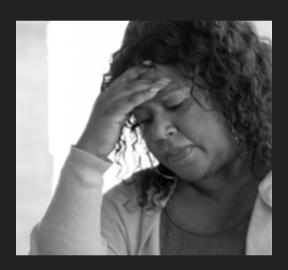
## Acknowledging the Unseen Diaper Divide:

Incontinence Product Access for All People



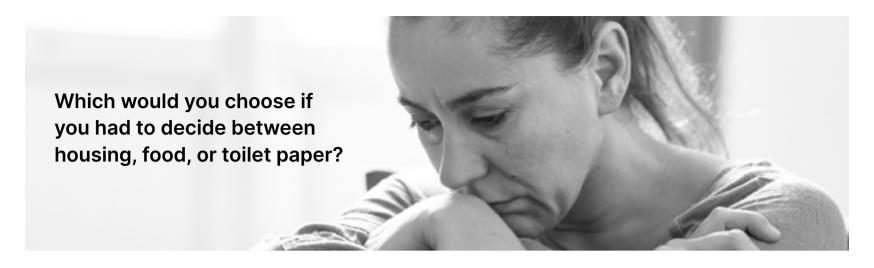






The need for diapers has never only affected children. People of all ages cannot afford the incontinence products they desperately require to maintain their health and quality of life. Like clean water and medical supplies, accessibility to incontinence products, such as diapers, is integral to living safe and fulfilled lives. Due to factors such as a lack of education, the COVID-19 pandemic, insufficient government assistance programs, health insurance regulations, and poverty in the United States, the Diaper Divide is widening. We need to advocate to impose solutions on our public health care regulations to close the Diaper Divide and help those living with incontinence.





While this choice may seem unimaginable to some, it is the reality for many people in the United States. Having to choose between spending money on hygiene products and other necessities, such as food, electricity, doctor's visits, and transportation, is a real and worsening problem for individuals with bladder and bowel control issues – a condition called incontinence.

However, the struggles and needs of these individuals are overlooked, partly because when the public thinks of diaper need, it thinks solely of its effect on infants and parents. And it makes sense- statistics showcasing lowincome parents' struggles to afford diapers for their little ones are shared across media outlets- a topic that's been acknowledged for years. While these young families are in need of diapers, unseen individuals with incontinence, such as people with disabilities and adults with bladder and bowel control problems, are in just as much need of access to incontinence supplies like diapers. A person's quality of life can be significantly impacted without the

required products.

In a survey conducted by Aeroflow Urology of over 1,000 people who manage incontinence themselves or care for a loved one with incontinence, 711 people report that they continuously struggle to afford incontinence products due to cost. While this statistic is shocking, it is just the tip of the iceberg. Lack of incontinence supplies causes a plethora of other serious consequences, such as mental and physical health issues, missed work or activities, and strenuous financial choices that should never have to be made by anyone.

While different groups of people struggle to manage their bladder and bowel issues without sufficient access to supplies, other problems continuing or arising across the nation are making it even more challenging to end incontinence product need. The COVID-19 pandemic has led to everincreasing costs, and bladder and bowel control supplies have unfortunately been included in the price hikes, making it harder for people to budget for them.

Government assistance programs put in place to help low-income families afford necessities are gravely lacking since incontinence products are not allowable expenses, leaving many people going without them. Inflation also affects those in the Diaper Divide, forcing families and individuals make more complicated decisions when choosing between bills, groceries, or incontinence products. Poverty rates among those needing products remain steady and are likely to increase due to inflation. Alongside these issues, the percentage of people in the geriatric population is rising, and with that, the need for senior incontinence supplies will too.

This white paper will explore how the Diaper Divide affects the unseen groups of people living without the medical supplies they require to live happy, healthy, and full lives. It will also discuss the role that current socioeconomic and societal factors play in the Diaper Divide.

#### The Basics of Incontinence

Those living in the Diaper Divide have bladder and bowel control problems called incontinence.

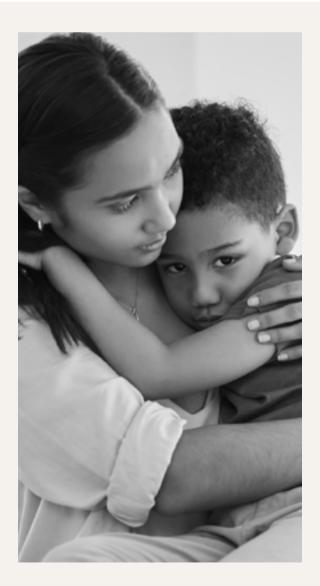
Incontinence occurs when a person loses control of their bladder (urinary incontinence (UI) and/or bowels (fecal incontinence)), leading to the unintentional loss of urine or feces. Any person of any age can develop UI or fecal incontinence, and an individual may be diagnosed with different types of each. All types come with unwanted side effects, such as:

- · Leaking urine or feces throughout the day or night
- Dribbling urine after voiding the bladder
- Voiding the bladder more frequently than usual
- · Feeling a sudden and strong urge to urinate
- Urinary or fecal retention (inability to empty the bladder or bowels)
- · Wetting the bed at night
- · Waking up multiple times at night to void the bladder

## What Is Incontinence?

Urinary Incontinence:
Loss of bladder control
resulting in the unintentional
loss of urine.

Fecal Incontinence:
Loss of bowel control
resulting in the unintentional
loss of feces.



# Who is in Need of Incontinence Products? In the Aeroflow Urology study: 34% are infants

22.5% are children

Almost 20% are parents or seniors

6% are children with disabilities

15.5% are adults



Little Ones Living in Diaper Need

#### Little Ones Living in Diaper Need

Typically requiring over eight changes per day, the cost of maintaining children's hygiene by purchasing new diapers out of pocket can cost up to more than \$61 each week, according to the study conducted by Aeroflow Urology. Other research shows that the average low-income US family spends around \$1,000 (1) on diapers yearly and that one in three families struggles to afford diapers. Diaper need can also financially devastate families due to continually replacing clothing and other items, such as bedding, mattresses, and furniture.

"My 4-year-old grandson is on the spectrum and still in diapers/pull-ups. Our only source of income is SSDI, and trying to keep him in pull-ups and diapers became so expensive that we couldn't self-sustain."

Nikki K., Aeroflow Urology customer

This struggle comes with serious consequences; it demands that parents repeatedly make the impossible decision of choosing one absolute necessity over another: Groceries or diapers, rent or diapers, utilities or diapers? Parents resort to keeping their children in soiled diapers for extended periods, reusing dirty diapers, and limiting food and fluid intake to prevent accidents.

"As a parent, the inability to provide for your child is the hardest feeling. Parents can experience guilt and shame and may need to make impossible sacrifices – such as reallocating money for food, transportation, or utilities towards diapers."

Samantha Eaker, DNP, CPNP-PC, Board-certified Pediatric Nurse Practitioner specializing in Pediatric Urology

#### 1 in 2

respondents limit food
or fluid intake for a
member of their household
in an attempt to save
incontinence products.

#### 2 in 5

respondents have to reuse dirty diapers or use products for an extended period of time due to lack of supplies.

#### 1 in 2

people have to miss experiences or activities due to not having enough incontinence products.





A lack of diapers also forces childcare centers to turn children away, causing family members to miss school or work to give at-home care, resulting in missed paychecks and less income to spend. Diaper scarcity affects mental health as well. Not being able to afford diapers for their child can give parents feelings of stress, anxiety, shame, and depression. Chronic stress can put a parent in "fight or flight" mode, which affects mental and physical health, decreasing their ability to care for their child properly. (3) Lack of diapers can even alter the parent-child relationship by harming "serve-and-return" interactions- when a child reaches out for interaction and the caregiver returns by reacting to the child's "serve." It can also alter secure parentchild attachments. Both of these are crucial to a child's brain development. Even sleep is affected by diaper scarcity; one study<sup>(4)</sup> found that diaper insufficiency causes sleep deprivation, which can lead to poorer brain development, memory loss, social-emotional issues, and problems with physical health.

"Many incontinence patients feel stress, anxiety, shame, and depression due to their condition.

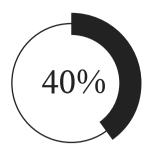
Their parents or loved ones may feel similarly, too."

Samantha Eaker, DNP, CPNP-PC, Board-certified Pediatric Nurse Practitioner specializing in Pediatric Urology

Worst of all, the lack of diapers leaves babies and children at risk for health issues. **Dirty diapers cause diaper dermatitis (DD)** and infections like urinary tract infections (UTIs).

Both DD and UTIs have been correlated<sup>(5)</sup> with the frequency of diaper changes; Fewer necessary changes increase a baby's risk of developing diaper-related problems.

Due to the severity of most UTIs and the lasting health effects they can have on children's bodies, it's imperative that the infection is treated, but treatment usually requires care from a pediatrician, which many low-income families may not be able to afford. Babies may even end up hospitalized with staph infections like methicillin-resistant Staphylococcus aureus (MRSA) which can occur after a baby develops even a slight skin wound.



Almost 40% of respondents have a family member who has experienced UTIs due to a lack of incontinence products.



Nearly half of respondents said a member of their household has experienced skin rashes due to a lack of supplies.



"Physically, a lack of incontinence supplies can lead to skin irritation and breakdown and possibly increase the risk of infections. Emotionally, this can cause embarrassment, seclusion, academic interruption or decline, and/or be socially prohibitive."

Samantha Eaker, DNP, CPNP-PC, Board-certified Pediatric Nurse Practitioner specializing in Pediatric Urology



Overlooking Disabilities & Medical Conditions in Children & Adults

#### Overlooking Disabilities & Medical Conditions in Children & Adults

Children and adults with disabilities are a majorly overlooked group living in the Diaper Divide. Many adults with disabilities have incontinence, and children with special needs are more likely to have bladder and bowel control issues compared (6) to those without special needs.

#### Incontinence in Children With Disabilities

In 2019, 3 million<sup>(7)</sup> children (under the age of 18) in the US were reported to have special needs, and it's also reported<sup>(8)</sup> that between 23 and 86% of children with physical or intellectual disabilities have UI.

#### Cerebral Palsy

One study<sup>(9)</sup> of 79 children with cerebral palsy (CP) showed that 54% had fecal incontinence and 80% had overactive bladder (OAB).

#### Autism

A study<sup>(10)</sup> conducted showed children with autism had increased rates of nocturnal enuresis (NE) and daytime urinary incontinence (DUI). The ability of children with autism to use the toilet was also delayed.

#### Down Syndrome

Another study(11) reported that children with Down syndrome were more likely to experience a delay in potty training and almost 50% of children who could previously use the toilet later developed regression that led to incontinence.

#### Incontinence in Adults With Disabilities

Adults with disabilities account for 26% (12) of the US population, many of whom will likely experience incontinence.

#### Autism

A study (13) of 22 adults with autism spectrum disorder (ASD) showed that UI occurred in 82% of adults and fecal incontinence occurred in 36%.

#### Down Syndrome

One study(14) showed that nearly 16% of adults with Down syndrome experienced UI and about 14% had fecal incontinence. Adults with CP also experience<sup>(15)</sup> high levels of incontinence.

The ability to afford incontinence products varies depending on a family's household income and financial responsibilities. Those with disabilities are more likely to live in poverty, therefore increasing their chances of facing incontinence product need. Reports show that children with disabilities are more likely(17) to live in poverty than those without. Due to a lack of proper educational resources, rejection from workplaces, social barriers, and disability-related expenses, adults with special needs are twice as likely<sup>(18)</sup> to experience poverty than adults without disabilities. Adults with disabilities may also experience homelessness; almost 1/4 of people experiencing homelessness in the US have a disability. (28)

While conditions like ASD and Down syndrome are disabilities that are commonly associated with incontinence, other medical conditions can also lead to incontinence in adults and children. These include Hirschprung's disease, attention-deficit hyperactivity disorder (ADHD), spina bifida, stroke, multiple sclerosis (MS), diabetes, spinal cord injury (SCI), muscular dystrophy, and more.

"Our daughter had issues with potty training long before any of her diagnoses [autism and epilepsy]. At the end of 2021, we got kicked out of our home and were practically homeless, jumping from place to place. Money was so tight, we had to discuss whether or not we'd skip meals or diapers. We chose meals."

Riley L., Aeroflow Urology customer



**Transportation** 

Incontinence products

People with special needs with any form of incontinence require incontinence products to manage their symptoms. Some people with disabilities need training pants as they learn to toilet train, while others may have a disability that never allows them to control their bladder or bowels. In these instances, the need for incontinence products lasts into adulthood, which can be outrageously expensive, causing families of loved ones with special needs to commonly face financial struggles, including food instability and issues paying rent, mortgage, or bills.(19)

Incontinence products are also a large portion of the total sum it costs to care for a person with a disability. Since the average family spends around \$1,000 on diapers per year, families raising children with disabilities to the age of 18 will most likely spend around \$18,000 on incontinence products out of pocket. In contrast, those raising a child throughout their lifetime (for example, to the age of 50) might spend around \$50,000.

Individuals with these types of medical conditions may experience incontinence throughout their lives. With out-of-pocket costs for incontinence products ranging up to \$61 per week, the total cost of caring for incontinence alone in an individual with a medical condition and incontinence can cost a fortune. Throughout a lifetime, incontinence care could amount to \$3,172 per year or over \$57,000 to the age of 18. On top of purchasing incontinence supplies, caregivers may need to pay for adaptive clothing, special household equipment or furniture, medical visits with specialists, surgeries, or special transportation.

#### Incontinence in Individuals With Underlying Medical Conditions

56 out of 68 patients with Hirschprung's disease were reported to have fecal incontinence, according to a PubMed study. (24)

A study<sup>(21)</sup> of children with ADHD reported that 5% experienced nocturnal enuresis, 5% experienced daytime UI, and 2.5% had fecal incontinence.

Stroke survivors reported UI and fecal incontinence, with 1 in 20 people aged 65 and younger reporting daily UI<sup>(22)</sup> and 7.2% of women aged 60 and older having fecal incontinence.

In one study of women, those who had diabetes were shown to have a 2.5 fold increased risk of experiencing UI. (26)

One study(20) reported that out of 9,700 MS patients, 65% experienced a form of severe urinary issues.

In one study of 179 young adults with spina bifida, 60.9% had UI, and 34.1% had fecal incontinence. (25)

43% of SCI patients reported experiencing UI less than once a week to daily. (23)

A study of 88 males with Duchenne muscular dystrophy showed that more than half had UI. (27)



The Role of Race in the Diaper Divide

#### The Role of Race in the Diaper Divide

It is evident that across the country, minority groups face educational, financial, and medical challenges, and those same barriers exist when it comes to the Diaper Divide. Diaper need disproportionately affects minority groups<sup>(29)</sup> partly because the rates of disability and poverty are higher among these groups.

In many cases, individuals in minority groups are more likely to have disabilities, and this is especially true for African Americans. According to the National Disability Institute, "14% of working-age African Americans have a disability compared to 11% of Non-Hispanic whites, and 8% of Latinos."(31) African Americans are also more likely than Non-Hispanic whites to have disabilities in each age group. Another study shows that Non-Hispanic African Americans have the highest prevalence<sup>(32)</sup> of severe disability among all racial groups.

#### Ethnicities of the Diaper Divide

In the Aeroflow Urology study:

135 Hispanic or Latino

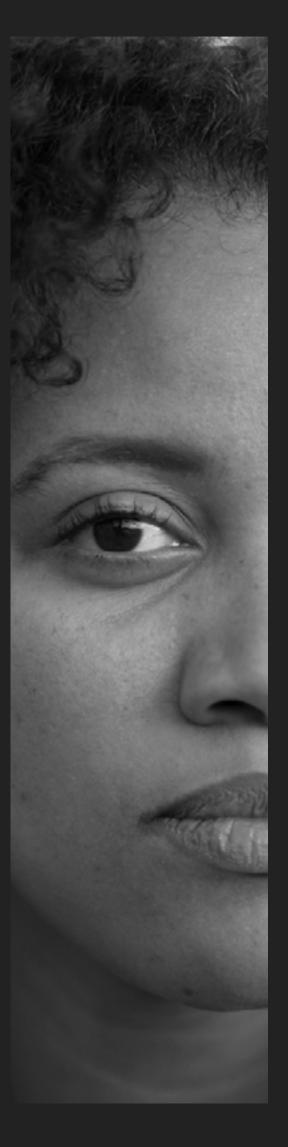
104 Black

102 Asian

20 American Indian

14 Middle Eastern

7 Native Hawaiian



Provider bias and historical representation of minority groups not receiving optimal healthcare is a huge barrier to addressing issues early and often. We see many minority groups not getting the care they need secondary to provider bias/lack of screening or avoiding medical offices altogether because of the historical negligence of the medical community to those minority groups."

Aleece Fosnight, MSPAS, PA-C, CSC-S, CSE, NCMP, IF, Board-certified Physician Assistant specializing in Sexual Medicine, Women's Health, and Urology



and Alaska Natives, almost 20% of African Americans, and 17% of Hispanics live in poverty compared to just 8.2% of White people and 8.1% of Asian people. (30) Supporting this, US Census Bureau data<sup>(33)</sup> also shows that 36% of African Americans with disabilities live poverty- the highest rate among any racial group. It has also been shown that diaper need occurs more frequently among unmarried Black and Latina mothers when compared to Non-Black and Non-Latina mothers and parents. (29) Another factor keeping minority groups in the Diaper Divide

the Federal Poverty Level (FPL), (35) a factor that may play a part in incontinence product affordability, especially if older minority groups have incontinence.

Race also determines the amount of grant money a nonprofit organization, such as a diaper bank, receives. If a person in a minority group runs a nonprofit, they will likely receive less grant money than their white counterparts. (36) This could potentially deprive families and minority communities from using diaper banks that are most ideal geographically.



The Senior Struggle

#### The Senior Struggle

Incontinence is prevalent among seniors, as incontinence naturally occurs as individuals age. According to studies (37) of seniors aged 65 and older conducted by the Centers for Disease and Control (CDC), around 50% of independent seniors, 39% of care facility residents, and about 45% of seniors receiving home health care experience incontinence. Despite its prevalence, affordable incontinence care is still out of reach for this age group.

Seniors also face housing insecurity, increasing the likelihood that they will be in need of incontinence products. According to the National Council on Aging, more than 15 million adults aged 65 and up face economic insecurity.(38) In senior housing facilities, up to \$1.5 billion is spent on UI care each year-(39) a remarkable cost for hygiene products that should be readily available in a senior community center. It's also estimated by the World Health Organization (WHO) that by 2023, 1 in 6 people in the US will be 60 years of age or older. (40) This means that the number of people with incontinence and need incontinence products, while also potentially facing the issues of healthcare coverage problems and low-income wages, will rise dramatically.

"With this increase in the older population, there will be a growing need not only for incontinence products but also for incontinence education, care, and treatment in geriatric populations, healthcare facilities, and nursing homes."

Susie Gronski, PT, DPT, Licensed Doctor of Physical Therapy, Rehabilitation Practitioner, Michigan-trained Sex Counselor and Educator

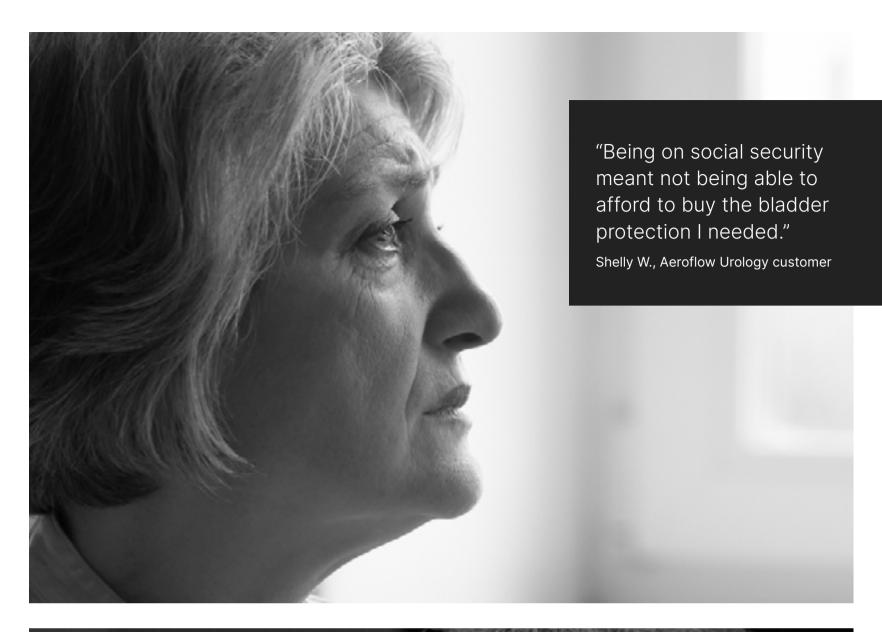
Fixed income is another challenge for seniors; forty percent of US seniors live on fixed-income payments alone, (41) and one in three seniors is economically insecure. (42) When faced with a tight budget, incontinence care becomes a choice for many seniors and their caregivers, forcing them to choose between groceries, bills, transportation, healthcare, and incontinence products.

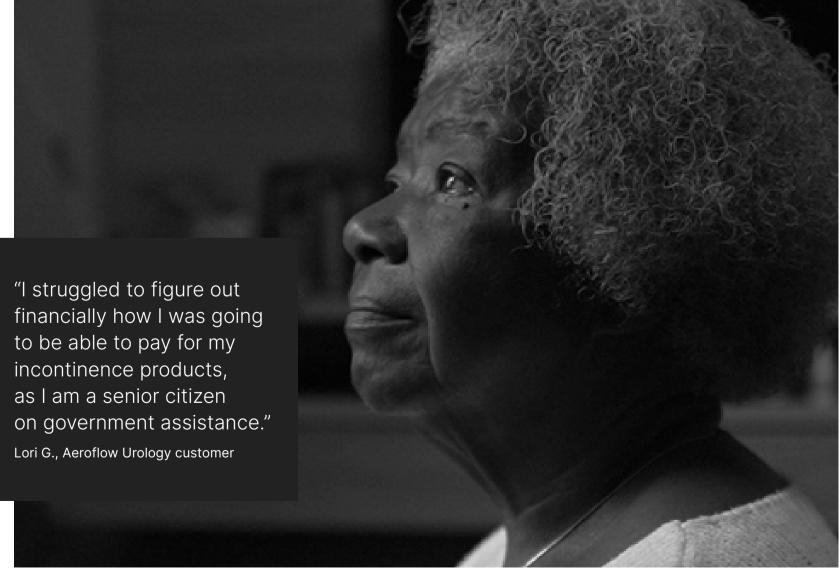
Healthcare may also pose a challenge for seniors. Medicare is a popular government health insurance option among older people in the United States, but it does not deem incontinence supplies as "medically necessary" items. This makes purchasing them out of pocket the only option for seniors already living off of incomes close to the Federal Poverty Level (FPL), placing them further into poverty and incontinence product need.



Nearly 20% (18.75%) of survey respondents are responsible for providing incontinence products to senior members of their households.









Living as an Adult With Incontinence

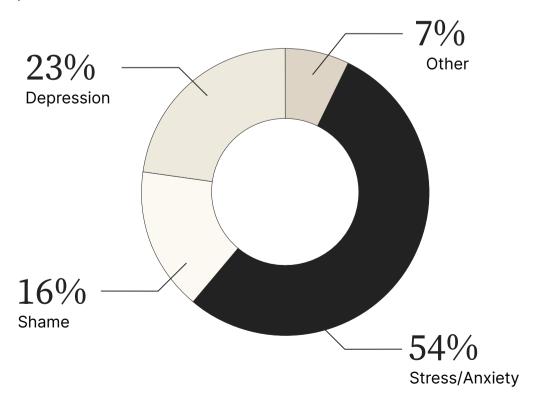
#### Living as an Adult With Incontinence

Over 25 million<sup>(43)</sup> American adults experience temporary or chronic incontinence which can impact their quality of life. Because many adults work, attend school, and attend social events, incontinence care is a vital part of functioning in daily life. Living in the Diaper Divide can make it impossible for individuals to continue life as usual. It may also cause mental, physical, and financial issues, and unfortunately, many adults experience this alongside incontinence product need.

Adult men and women may develop incontinence for various reasons, including childbirth, menopause, prostate issues, aging, injury, and more. However, due to the stigmas surrounding incontinence in adults, many individuals avoid speaking about their conditions with family members, friends, and even healthcare providers. One study showed that 52 % of females with diagnosed incontinence felt they had to hide their symptoms due to shame or embarrassment, even from their own healthcare providers. (44) Incontinence doesn't just take a mental toll on women; adult males experience stress and anxiety due to shame or embarrassment (45) as the stigma surrounding men and incontinence remains a significant societal problem.

#### Impact of Incontinence on Mental Health

Respondents of the Aeroflow Urology survey report the following feelings when managing incontinence and needing incontinence products.



"I'm only 52 years old. [Incontinence] is very embarrassing. It's expensive to buy these products. When you're single, it's hard coming up with money when you don't make a lot of money."

Michael F. Aeroflow Urology customer

"I live on a fixed income, and when I started having bladder weakness, I didn't know how I was going to stretch my income to add pads to my needs."

Rhonda D. Aeroflow Urology customer

"At 37 years old, I was diagnosed with severe epilepsy and lost bladder control during a seizure. I'm also not able to make it through the night, and [I] leak during daily activities."

Teresa R. Aeroflow Urology customer

Both men and women can feel shame, anxiety, depression, embarrassment, and other mental health issues when confronted with incontinence symptoms. Nearly 40% of individuals in the Aeroflow Urology study report feeling stress and anxiety when managing incontinence and facing incontinence product need.

"Stress and anxiety also affect the pelvic floor muscles, which may cause them to tense involuntarily, leading to pelvic floor dysfunction, which can exacerbate bladder issues."

Susie Gronski, PT, DPT, Licensed Doctor of Physical Therapy, Rehabilitation Practitioner, Michigan-trained Sex Counselor and Educator

Managing symptoms of incontinence also causes adults to self-isolate. Over half of respondents from the Aeroflow Urology survey (53.8%) report that they or someone in their household has missed activities due to not having enough diapers.

"Avoiding social activities has been correlated with isolation which increases depression and other mental health concerns. Stress and anxiety can also lead to worsening urinary incontinence, and the cycle worsens."

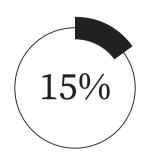
Aleece Fosnight, MSPAS, PA-C, CSC-S, CSE, NCMP, IF, Board-certified Physician Assistant specializing in Sexual Medicine, Women's Health, and Urology

Missed income is another issue for adults in the Diaper Divide. Many adults with incontinence are part of the working population and manage symptoms in the workplace. Without access to required supplies, individuals may miss days of work to avoid the embarrassment and challenges of managing accidents in public, leading to less income.

"People are calling out of work or have been let go from their job secondary to needing to go to the restroom."

Aleece Fosnight, MSPAS, PA-C, CSC-S, CSE, NCMP, IF, Board-certified Physician Assistant specializing in Sexual Medicine, Women's Health, and Urology

Missed paychecks may also contribute to the poverty rate among US adults, with 54% of individuals ages 18 to 64 living in poverty.(46)



Over 15% (15.57%) of adults surveyed report they purchase incontinence products for themselves.



here is a tremendous impact on urinary incontinence and mental health. The amount of shame and insecurity felt by these individuals is palpable. There is fear associated with urinary incontinence - will I smell, will I wet my pants, where is the next restroom? - and this leads to avoidance and anxiety."

Aleece Fosnight, MSPAS, PA-C, CSC-S, CSE, NCMP, IF, Board-certified Physician Assistant specializing in Sexual Medicine, Women's Health, and Urology



The Pandemic Effect



#### The Pandemic Effect

The COVID-19 pandemic has created an even greater need for incontinence products due to cost increases, COVID-19's effects on the body, and the remote work environment's effect on physical health.

The cost of diapers has increased by about 22% since 2018, (47) whereas 2021 brought a 20% (48) increase in cost alone. As prices rose during the pandemic, low-income families struggled to care for incontinence, with around 40% of caregivers reporting high diaper need during the height of COVID-19. (49) COVID-19 itself has impacted how many people need incontinence

products; individuals who tested positive for the illness experienced new or an onset of symptoms related to UI. The sedentary pandemic lifestyle also promoted symptoms of UI in people with and without existing bladder issues. Over 2,500 remote workers reported that they experienced increased urges to urinate and increased trips to the bathroom.(50)

As life after the pandemic resumes, many people who require incontinence products are stuck navigating new, more strenuous health and financial hurdles.



Failing Government Support

#### Failing Government Support

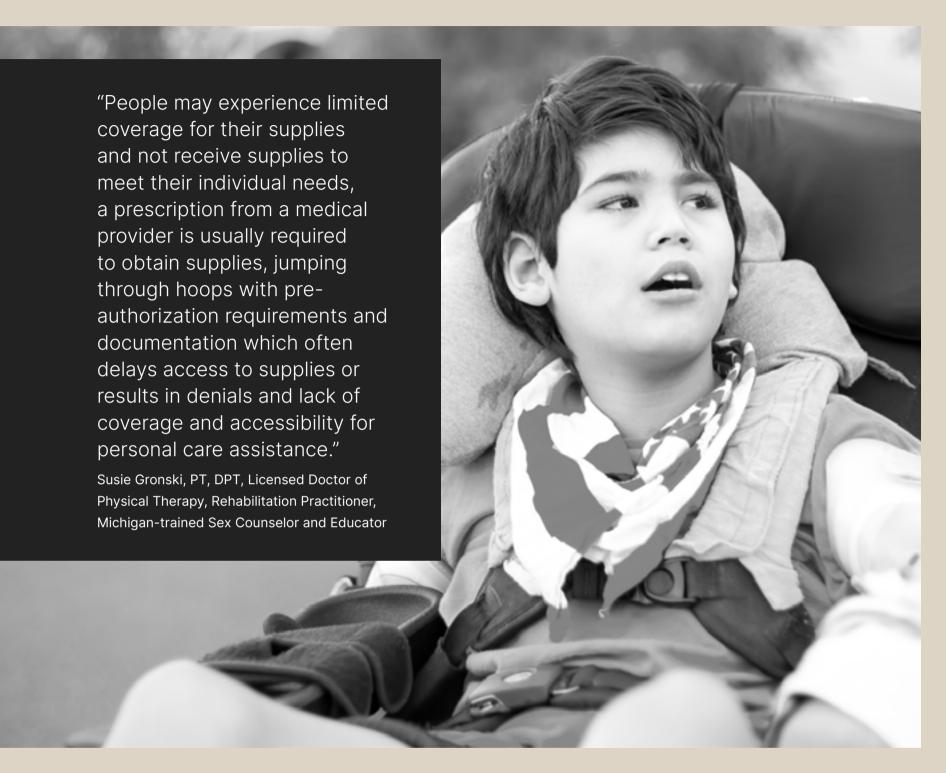
Government assistance programs, such as the Women, Infant, and Children (WIC) program and the Supplemental Nutrition Assistance Program (SNAP), put in place to help those living on low income afford necessities, largely fail people in need of incontinence care products.

These programs do not allow recipients to purchase diapers or other incontinence products with their allotted funds. Despite increased funds for local diaper banks and federal stimulus payments during COVID-19, diaper need is at the same level as before the pandemic. (51) Even government programs that do allow incontinence products to be purchased with allotted funds are failing those in need. The Temporary Aid to Needy Families (TANF) program does allow recipients to use their funds to purchase incontinence supplies. However, current prices are simply too high to fit into given budgets. If families were to use their TANF funds for

incontinence products, they'd be spending between eight and 40% on that alone. (52) The amount of money TANF beneficiaries receive has also decreased 20% in 38 states from 1996 to 2014. (53) The Child Care Development Block Grant (CCDBG) program also leaves those in need of diapers with unmet needs. While childcare centers are given funds under this program, they're not required to supply diapers for children, and centers that would attempt to use their subsidies for diapers do not receive enough money to afford them.

Since the demand for diapers increased during the pandemic, some diaper banks now lack adequate supplies. Transportation to and from diaper bank locations, limited product availability, and eligibility criteria also hinder recipients' probability of taking full advantage of diaper bank programs.





Insufficiency of government assistance runs deeper than supplemental programs and diaper banks. Even the most widely-used health insurance programs-Medicare and Medicaid-leave people in the Diaper Divide feeling neglected. Over 86,000,000<sup>(54)</sup> individuals are currently enrolled in Medicaid and more than 65,000,000<sup>(55)</sup> people enrolled in some form of Medicare.

While Medicaid deems incontinence products "medically necessary," beneficiaries first must meet eligibility requirements for the program itself, then jump through hoops to prove the protective products

they need are necessary for managing health issues. Not all individuals enrolled in Medicaid have their incontinence products covered- additional criteria must be met in order to qualify. Because Medicaid varies state-by-state, some people may not be able to get their supplies covered by Medicaid. On the other hand, Medicare doesn't consider incontinence supplies a necessity and the regulations are the same throughout the United States. This leaves many seniors on Medicare who likely have incontinence without coverage for required products that maintain their dignity and health.



Poverty Levels at Play

#### Poverty Levels at Play

Poverty plays a leading role in the Diaper Divide for an obvious reason: Incontinence care products can be expensive, which individuals with incontinence living in poverty can't and shouldn't have to afford out of pocket. In 2021, there were 7.4 million<sup>(56)</sup> US families living below the FPL, and in previous years, the poorest percentile of families spent nearly 14%<sup>(57)</sup> of their income on diapers for their loved ones. Poverty rates among older adults (65 and older) also recently increased.<sup>(58)</sup>

Many families and individuals who struggle to afford incontinence care products live at or below the FPL. The current FPL<sup>(59)</sup> in the US is \$14,580 for individuals; \$19,720 for families of two; \$24,860 for families of 3; \$30,000 for families of four. The largest group of respondents from the Aeroflow Urology survey live at or just above the FPL, with nearly 20% (19%) living between \$25,000 and \$49,999 per household. Almost 10% (9.46%) report a household income of \$10,000 to \$24,999, and 4.5% report between \$0 and \$9,999.

## Household Income for Those with Incontinence

4.80% - \$200,000+

2.04% - \$175,000 - \$199,999

3.19% - \$150,000 - \$174,999

10.28% - \$100,000 - \$124,999

15.90% - \$75,000 - \$99,999

18.73% - \$50,000 - \$74,999

19.00% - \$25,000 - \$49,999

9.46% - \$10,000 - \$24,999

4.50% - \$0 - \$9,999

6.72% - Prefer not to answer

"Living in low-income or poverty conditions can play a role in accessing care - cost, paying for medication, insurance coverage for a procedure/surgery, and taking time off for those procedures can be a huge barrier."

Aleece Fosnight, MSPAS, PA-C, CSC-S, CSE, NCMP, IF, Board-certified Physician Assistant specializing in Sexual Medicine, Women's Health, and Urology

People in poverty are more likely to experience incontinence product need because they have less income, leaving less finances to spend on products, and because they are more likely to have a disability that causes incontinence. Individuals in poverty typically have less access to basic necessities, such as household appliances and nutritious foods. One survey reported that 380,000 poor households in the US did not have plumbing, including running water, showers, bathtubs, or a working toilet. (60) One in eight people living at the FPL live in households without adequate food supplies. (61) Without the basic resources needed to practice proper hygiene and maintain a nutritious diet, physical illness, such as UTIs and other infections, may develop, requiring

medical care visits that some people cannot afford. Bills from medical visits may also force unwell individuals to make difficult financial decisions, such as choosing medical treatment, food, or incontinence products.

The relationship between poverty and disabilities is cyclical; living in poverty raises a person's likelihood of having a disability, (62) and those with disabilities are more likely to have lower incomes, thus, are more likely to fall into poverty. In cases where a person with a disability has incontinence, they require products to manage their symptoms, which creates further financial burdens, keeping them in this cycle of poverty.

#### **Aeroflow Urology Study**

Aeroflow Urology conducted a survey of **over 1,000 people living with incontinence** or caring for someone who had the condition. This new research showcases how the Diaper Divide affects different groups of people and demonstrates how incontinence products need is amplified by the current issues in the US. Our Findings:



70% of respondents have **not been able to afford diapers,** while **72% continuously struggle** to
buy products due to affordability.



66% of those surveyed reported that they have had to **choose between buying incontinence products and other necessities,** such as food, electricity, etc. on a frequent basis.



40% of respondents stated they have had to reuse products for an extended period of time because they could not afford to buy new ones.

#### 48%

of respondents **limit food or fluid intake** for a member of their household in an attempt to save incontinence products.

#### 53%

stated they have had to miss out on important events and activities because they couldn't afford enough diapers for the occasion.

#### 2 in 3

admitted their mental health has been negatively impacted by needing diapers or caring for someone with incontinence, with 40% stating their stress and anxiety levels have increased.

#### 1 in 3

shared they have experienced a

more severe health complication
because they did not have
enough products to properly
handle their incontinence, with
70% stating those complications
involved an infection, UTI,
increased incontinence
or skin irritation.

#### 2 in 3

reported their healthcare
provider had not provided any
assistance in acquiring products,
and 55% stated they have
received zero resources to help
manage caring for someone
with incontinence.



Almost 80% of those surveyed wish there were more resources available to help them navigate incontinence and bladder problems and caring for someone with these issues.



Closing the Diaper Divide



#### Closing the Diaper Divide

incontinence products The lack for children. adults, and seniors with disabilities. medical conditions, incontinence, as well as the disparity minority groups in need of diapers face, are all continuing and growing problems in the US. This need, and the issues of inflation, rising diaper prices, poverty rates, and the COVID-19 pandemic make up the Unseen Diaper Divide. Thankfully, there are ways to understand these issues and close the divide.

Some solutions posed to caregivers in the past, such as buying diapers in bulk and using cloth diapers, have proven ineffective for lowincome families due to a lack of resources. Bulk items typically come in enormous quantities, which are packaged in boxes that are too large to carry home by way of public transportation, leaving caregivers stranded. Furthermore, while reusable cloth

diapers may seem like an answer, there is a high probability that households with income at the FPL may not have a washer or dryer. On top of that, laundromats don't allow soiled diapers to be washed in their facilities, leaving families with the inability to clean and reuse them properly. These previously suggested solutions to end diaper need have not addressed the fact that the problem of diaper scarcity runs deep and is intertwined with more significant issues such as lack of government assistance programs, unaffordable costs of living, and strict insurance regulations. In order to close the Diaper Divide, individuals with and without incontinence and those with legislative power need to focus on creating impactful solutions that extend to all people affected by diaper scarcity.

#### 6 Ways to Close the Diaper Divide

#### 1. Educate About Incontinence and Speak Openly

Education is the first and simplest way to begin closing the Diaper Divide. Those without incontinence need to be made aware of the genuine health risks involved with incontinence product scarcity. Those without incontinence need to be made aware of the genuine heath risks that come along with incontinence product scarcity— especially because many people often don't even know what incontinence is. It's critical that information is shared so people can understand why living without incontinence products is unsanitary, uncomfortable, and sometimes dangerous.

Apart from educating about the negative side effects of incontinence product scarcity, people should acknowledge the previously unseen groups of people that are very much in need of incontinence products. t's not just infants and parents who are in diaper need; individuals with special needs, minority groups, families in poverty, and seniors all struggle to afford the products necessary to maintain their dignity and quality of life. Exploring how these groups of people are affected by current financial and healthcare elements in the US will shed light on the importance of incontinence product access.

Lastly, those with and without incontinence can help end the stigmas surrounding bladder and bowel control issues. Although incontinence is widespread, the ideas that it's shameful, embarrassing, or gross tend to live on in society. The truth is that any person of any age can develop incontinence for any related reason. The condition itself already affects mental health, causing anxiety, depression, and shame. Stigmas perpetuating these ideas do not need to be added onto individuals' daily lives. Open discussion around incontinence topics may help to dissipate stigmas and let individuals with the condition know they're supported.

Healthcare providers and communities also need to focus on strengthening their resources around incontinence for people of all ages. If providers and communities spoke about and promoted resources, like support groups, diaper banks, and specialists, those with bladder and bowel conditions would have a higher chance of navigating their conditions and finding treatment.

"There is lack of awareness of the resources available and that is where the problem lives. Reaching out to your local health department or social services department can be a great start. Calling hospital social services can also be a good source for options communities have for urinary incontinence needs. Even calling urology offices and speaking to a nurse navigator or office manager can lend you some good resources."

Aleece Fosnight, MSPAS, PA-C, CSC-S, CSE, NCMP, IF, Board-certified Physician Assistant specializing in Sexual Medicine, Women's Health, and Urology

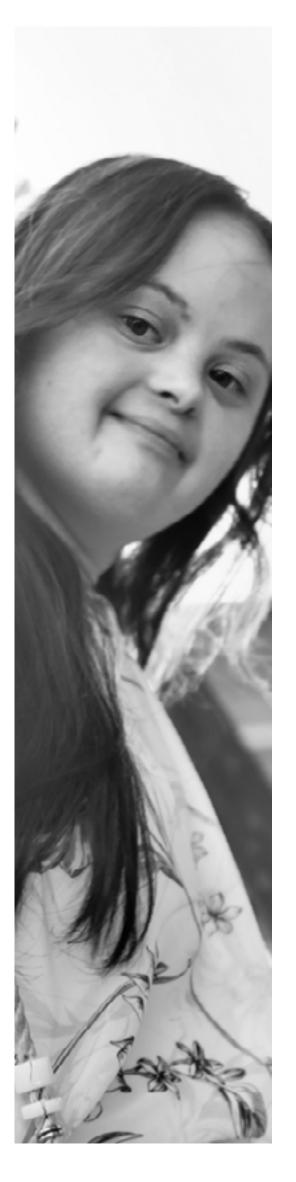
#### 2. Federally Categorize Incontinence Products as Medical Necessities

After educating the public about the health risks associated with a lack of diapers comes the solution of federally categorizing diapers and other incontinence products as medical necessities. This nationwide classification would force state Medicaid programs to expand their individually-set coverage requirements for absorbent products, overriding their regulations and giving many children, adults, and seniors on Medicaid the ability to receive incontinence products for free. A federal bill that classifies incontinence products as medical necessities would also allow Medicare to expand its coverage for these supplies, ending diaper scarcity for recipients- particularly seniors- with incontinence by allowing them to receive them through their healthcare plan. Classifying incontinence products as medically necessary may also encourage government assistance programs to loosen their restrictions on what can and can't be purchased with recipients' allotted funds, giving those in the programs the opportunity to buy incontinence products with the money provided.

### 3. Increase Assistance Program Funding & Create Better Programs

Apart from encouraging programs like WIC and SNAP to change regulations, increasing state and government funding for these programs or creating more efficient programs could help close the Diaper Divide. State-run assistance programs could redirect a larger portion of their assistance spending to programs that help low-income families or families with people with disabilities afford basic necessities. States could also lower their eligibility income requirements for families applying for TANF cash assistance programs.

Diaper banks are another assistance program that need to be altered to better meet the needs of those in the Diaper Divide. Diaper banks are currently funded by private and corporate donations and lack the money necessary to provide incontinence products to all families and individuals in need. Diaper banks also commonly lack product variety, with some only supplying certain sizes and brands that don't fit all people or protect against their level of leakage. With the rise in cost of living, housing instability, and diaper prices, these distribution facilities will likely experience product shortages in the near future. Federally funding diaper banks would make them more efficient and allow them to provide more products to more families, helping to close the Diaper Divide.



#### 4. Eliminate the Incontinence Product Tax

Introducing bills that eliminate diaper and incontinence product tax would also aid in closing the Diaper Divide. Because adults and seniors in need of incontinence products are commonly overlooked, ensuring that the tax elimination bill is introduced would end taxes for adults as well as pediatric incontinence supplies would be an important part of this solution.

#### 5. Give Direct Aid to Families & Individuals in Need

Another way to potentially end diaper need is to give direct aid to low-income families and individuals in need in the form of diaper vouchers or allotted funds. Aid could be given through government assistance programs such as SNAP, TANF, or WIC.

#### 6. Expand Medicaid & Medicare Coverage for Those with Incontinence

Medicaid and Medicare plans don't currently offer enough coverage for all of those with incontinence, leaving them without the products they require. In order for every person with bladder and bowel conditions to be able to afford the products they need, policies must be changed at both state and national levels. State Medicaid programs should eliminate certain regulations that block people from receiving incontinence supplies, and Medicare must finally deem these products necessary for them to become nationally accepted under its policy.



#### What You Can Do

You can help close the Diaper Divide and end diaper need by signing Aeroflow Urology's petition to expand insurance coverage for incontinence products and make incontinence products medically necessary under Medicare. You can also share your story about what it's like to live in the Diaper Divide.





#### Conclusion

The Diaper Divide is an issue that spans far beyond parents and children- it touches every individual with bladder and bowel issues, whether they are managing leakage for a short period of time or a lifetime. Additionally, it places financial burdens on families and individuals, and causes mental health issues and severe physical health problems.

Closing the Diaper Divide will positively affect families and individuals in need in more ways than one. Receiving incontinence products improves parents' moods and child happiness and health, allows for more opportunities to attend school and work for adults and children, and makes it easier for families and individuals to pay for other necessities that support a better quality of life. Advocating for other individuals, such as adults and seniors with incontinence, individuals with medical conditions and disabilities, and minority groups facing financial or housing barriers, could give them proper access

to incontinence supplies, lessening their financial issues and increasing their quality of life.

By recognizing that incontinence product need is a **public health concern** and advocating for its inclusion in health insurance plans, we can ensure that every family has access to an adequate supply of products. **This requires collaboration among policymakers, nonprofits, businesses, healthcare providers, and community organizations.** It necessitates the allocation of resources and the development of sustainable solutions to address the root causes of incontinence product scarcity, such as poverty, lack of affordable products, and limited access to basic necessities.

All references cited throughout this white paper can be found here.



#### <u>AeroflowUrology.com/DiaperDivide</u>











