QUARTERLY report

Volume 26, No. 1 | 2024

Black History Month

Lost Dreams Awakening (LDA), a registered 501c3 nonprofit, Recovery and Wellness Center, located in New Kensington, PA, founded by an African American couple (Dr. VonZell Wade and Laurie Johnson-Wade) both in SUD recovery since 1991, is Celebrating Black History Month 2024 in various ways. Here are a few:

We are "Addressing Health Equity in Substance Use Disorders (SUD) during Black History Month and Beyond" using a multifaceted approach.

It's crucial to recognize and address the unique challenges and disparities that the African American community faces in accessing effective treatment and recovery support for SUD.

Here are some measures we believe can be effective:

1. **Increasing Awareness and Education:**

   Use Black History Month as a platform to increase awareness about SUD in the African American community. Educational campaigns can focus on destigmatizing substance use disorders and promoting understanding of them as medical conditions.

2. **Cultural Humility in Treatment:**

   Ensure that SUD treatment providers are trained in cultural humility to effectively serve African American individuals. Cultural humility is a concept and approach in interpersonal relationships and professional practice, emphasizing ongoing self-exploration, self-critique, and a lifelong commitment to learning and understanding different cultures. It's particularly relevant in fields such as healthcare, social work, education, and any environment where individuals interact with people from diverse backgrounds. If needed, LDA can support providers with evidence-based, data-driven training or free resources.

3. **Accessible and Affordable Treatment:**

   Advocate for and work towards making SUD treatment more accessible and affordable in and for African American communities. This could involve supporting policies that expand healthcare coverage and reduce costs.

4. **Community-Based Interventions:**

   Develop and support community-based interventions that are tailored to the needs of African American communities. These interventions can be more effective when they are rooted in the community and involve peers, leaders and community-based organizations.

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PRO.A is now on FACEBOOK – "like" us at www.facebook.com/PaRecoveryOrganizationAlliance

Nation Peer Recovery Center of Excellence

PRO•A Executive Director William Stauffer was honored to be invited to participate in the National Peer Recovery Center of Excellence annual retreat which took place on January 17th and 18th in Kansas City, MO. The Peer Recovery Center of Excellence is a peer-led national center that provides training and technical assistance related to substance use disorder recovery. Housed at the University of Missouri–Kansas City (UMKC), the center was authorized under Section 7152 of the SUPPORT Act for Patients and Communities and funded by the Substance Abuse and Mental Health Administration (SAMHSA).

The Center's strategies for training and technical assistance are organized into the following core areas of focus:

- Clinical integration of peer support workers into non-traditional settings;
- Building and strengthening capacity of Recovery Community Organizations;
- Enhancing the professionalization of peers through workforce development;
- Providing evidence-based and practice-based toolkits and resource information to diverse stakeholders

For more information about the Center, email info@peerrecoverynow.org

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Black History Month

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5. **Addressing Structural Determinants of Health:**

   Recognize and address the broader social determinants of health that contribute to SUD, such as poverty, unemployment, and exposure to trauma and weathering. Efforts can include advocating for economic development, housing stability, and trauma-informed care.

6. **Supporting Research and Data Collection**

   Support research that focuses on SUD in the African American community to better understand the unique challenges and effective interventions. Ensure that data collection includes racial and ethnic demographics to inform equitable policy and program development. LDA is pleased to be involved in such projects—past and present. Please contact us for the findings.

7. **Mental Health Services Integration**

   Integrate quality mental health services with quality SUD treatment, recognizing the high comorbidity between mental health disorders and substance use disorders, and the importance of treating both.

8. **Peer Support and Recovery Programs**

   Promote peer recovery support programs that are culturally sensitive and include coaches or helpers from similar backgrounds. Such programs offer relatable guidance and proven support.

9. **Policy Advocacy**

   Engage in advocacy to influence policies that impact SUD treatment and prevention in the African American community. This includes advocating for criminal justice reform, as the war on drugs has disproportionately affected African Americans.

10. **Continued Celebration and Support Beyond Black History Month**

    Ensure that the focus on SUD and health equity continues beyond Black History Month. Ongoing commitment is crucial for making lasting changes and truly addressing health disparities in SUD treatment and prevention. By taking these measures, the goal is to create a more equitable and effective approach to addressing SUD in the African American community, recognizing the unique challenges and barriers faced and working towards comprehensive, culturally sensitive solutions is a sure way forward.

LDA will be celebrating Black History Month in person on February 28, 2024, at 408 8th Street, New Kensington, PA, 15068, and joining a Block Party hosted by the national recovery group —Black Faces Black Voices. LDA doors will open at 5:00 PM and the BFBV Virtual Celebration (showing on LDA Big Screen) starts at 6:00 PM.

This event is OPEN to ALL and will be FREE to attend. We will have FREE food and fun (including a Soul Train Line) for ALL.
If you cannot attend in person, but want to join us—register here!

Help improve your mental well-being while you're in recovery.

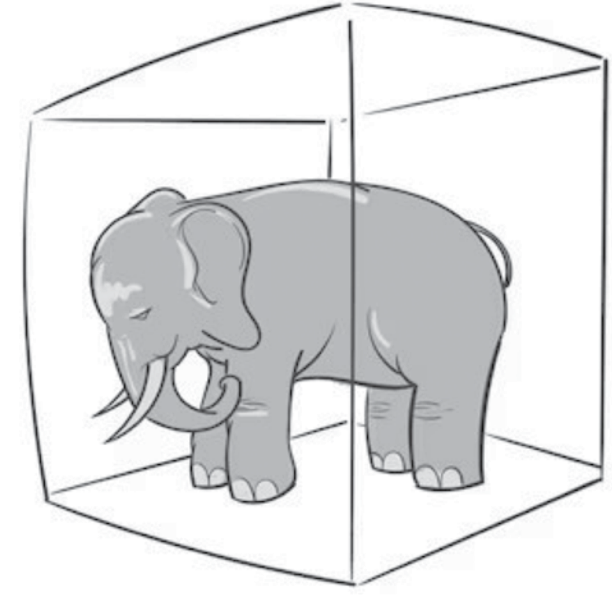
Learn tobacco-free coping skills.

Tobacco recovery *is* recovery. Let's talk about it.

In a recent survey of Pennsylvanians in recovery, more than **70%** said learning tobacco-free coping skills is helpful to mental health or substance use recovery. Get free help at **tobaccofreerecoverypa.com** and **1-800-QUIT-NOW.**

Cerebral Hypoxia & the "Opioid Epidemic"—

An Elephant in the Room



Addiction is a vexing challenge in our society. One it is prudent to look at what is not being spoken about, perhaps with as much or more focus than what is getting attention. Where are the proverbial elephants in the room? Cerebral Hypoxia and related brain injury associated with overdoses is one of those elephants in the room. Roughly 3 million Americans have an OUD. In 2017, 967,615 nonfatal drug overdoses were treated in emergency departments, in the US. In 2021, according to the CDC, over 106,000 people died in the United States from drug overdose, but what happens to survivors? Do they survive over the long term? Are there short or long-term functional impairments as a result of an OD? Despite hundreds of thousands of deaths and millions of overdose reversals, the answer is we do not know much at all about the implications of surviving an OD for persons experiencing brain injury and its clinical and recovery considerations.

Efforts to date have focused on first aid, reversing death. It is a critical area of focus. Increasing access to Naloxone is vital to our efforts to save lives. According to a CNN article 1.2 Million doses of naloxone were distributed by retail pharmacies, in 2023, which is only one major source of distribution. One large-scale national study showed opioid overdose deaths decreased by 14% in states after they enacted naloxone access laws. Another study suggests that because of changes in drug use patterns, with the increase of fentanyl and fentanyl in combination with drugs like xylazine or methamphetamine are resulting in more rapid overdose onset and the narrow window for treatment with overdose reversal agents. This last point suggests the stakes are getting higher.

Naloxone is vital as this 2017 CNN article notes, yet it is only first aid. Naloxone temporarily reverses death 93% of the time. Those who survive often die within the year. Another study analyzed Medicaid records from 45 states to look for causes of death in more than 75,000 adults who were treated for an OD between 2001 and 2007. More than 5,000 of the adults died within the first year following an OD —24 times the death rate found in the general population.

The most common causes of death were those related to drug use (25%), diseases of the circulatory system (13.2%), and cancer (10.3%). The data show that adults in this population are substantially more likely to die of these causes than adults in the general population. We need to get people into treatment and recovery if we are to make a dent in these horrific stats. This is a consequence of framing a multimutated, polysubstance addiction crisis as an opioid or overdose crisis, which leads to tunneled senses in both people and systems.

Brain injury impacting cognition may be a major barrier to healing. This is one of our most profound public health crises, one that has been unfolding over the last two decades, yet we have not studied the implications and clinical considerations of a key factor in helping people survive and heal from it. How is it possible we know so little about overdose related brain injury? It is likely commonplace, but rarely studied.

Cerebral hypoxia is a condition where the brain doesn't get enough oxygen. It can kill brain cells and lead to brain damage and death. It includes symptoms such as difficulty paying attention, poor judgment and decision making and memory loss. How many people have impaired cognitive functioning in the very moments they are offered further help? We don't know and have not bothered to methodically explore this question.

There has been disturbingly little focus on the prevalence of cerebral hypoxia or related brain injury in overdose survivors. One meta-analysis of 79 journal articles published between 1973 and 2020 found it was probable that brain injuries and neurocognitive impairments were associated with opioid overdoses. The paper notes that additional research is needed to understand its onset, characteristics, the duration of potential incidence and clinical care implications. This is vital information needed to save lives, and we do not yet have it!

Another paper published in Europe in 1999 reviewed autopsies of 100 intravenous opioid drug users suggests in that era, with lower potency opioids less likely to be used in combination with other drugs, between 5% and 10% of heroin addicted persons may have brain injury associated with their use. The paper notes that severe mental disturbances are likely in affected persons. A 2019 paper, Neurologic, Cognitive, and Behavioral Consequences of Opioid Overdose: a Review, notes that further studies are needed on the neurologic, cognitive, and behavioral sequelae of opioid overdose in order to develop an effective long-term treatment strategy to manage the healthcare needs of this population.

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Cerebral Hypoxia & the "Opioid Epidemic"—
An Elephant in the Room

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This article Fentanyl Overdoses are a Hidden Health Crisis, by Dr. Keith Ahamad, a Vancouver-based addiction specialist notes that paralysis, brain death and organ failure are things he regularly sees. Why do we rarely hear about this potential outcome for overdose survivors. The numbers are staggering. A paper from 2017 reviewed records from 162 hospitals in 44 states, between 2009, and 2015. They documented 2.7 million admissions with 4.1 million requiring ICU care an increase of 34% over the period of review. It does not delineate how many of these cases relate to overdose related brain injury. This 2018 NYT Op-ed, An Overdose Left Him With Brain Damage. Now What? It is the story of Andrew Foote, a young man loved by family and friends who survived an overdose only to experience severe brain injury that has incapacitated him for life. How many of these tragic stories are out there? How can we prevent these cases without a focus on them?

We should have had this data decades ago. How have we have failed to focus on these vital considerations with perhaps the most significant public health crises in the last one hundred years? We need to understand the clinical and policy implications of neurological impairment in overdose survivors to improve interventions.

Questions to consider:

- If this type of brain injury is prevalent among overdose survivors, how does it impact their reasoning capacity either in the short term or long term?
- How does overdose related cognitive injury impact clinical care?
- How do we screen for the capacity to make reasoned decision for overdose survivors who may experience this type of brain injury? Are we doing such screening systemically?
- How can clinicians and laypersons identify potential brain injury in overdose survivors and how do we get this information out to the impacted communities as quickly as possible?
- How does multiple drug use impact overdose related brain injury?
- Do emerging drug trends such as the combination of fentanyl with xylazine as an example, impact the prevalence of brain injury in persons experiencing overdoses?
- What is the prevalence of brain injury in persons who have experienced multiple overdose reversals?
- What can we learn from the treatment of other conditions in which a person may not be cognitively functioning?
- Would it be ethical to allow a person in diabetic shock for example to refuse treatment to stabilize their blood sugar levels? What is different about a person cognitively impaired following an overdose?
- If we have not invested in understanding this fundamental issue, what else don't we know about how to more effectively help people survive and heal from an opioid use disorder?

We must address this major deficit in our knowledge base while asking hard questions about why it has been allowed to occur. With just under one million people presenting at hospital emergency departments across America, how is it humanly possible that we never even bothered to rigorously study cognitive impairment related to overdose related brain injury and its impact on survival rates and healing?

Can we imagine this being tolerated for any other condition?

Let's talk about the elephant in the room!

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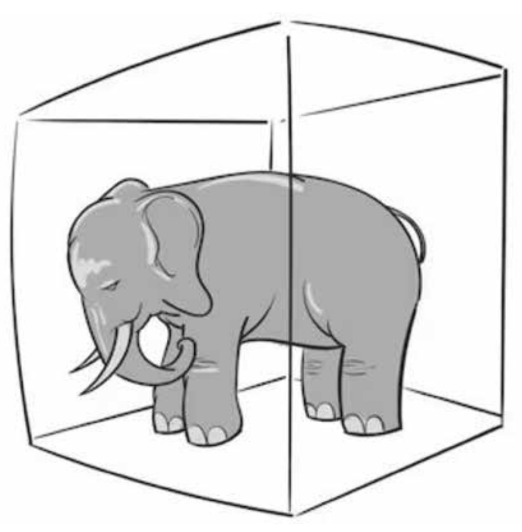

An OASIS of Healing for Family Recovery

Break the silence
End the stigma
Never forget

by Rhonda Miller, CFRS, Certified Grief Educator, Executive Director, Speak Up for Ben, Inc. & OASIS Community Center

On the peaceful banks of the Monocacy Creek in Bethlehem stands a stately 220-year-old fieldstone farmhouse. Surrounded by majestic trees, its grand porch beckons the weary visitor to enter and find rest. But this historic property is not a private residence. It is home to the OASIS Community Center, Pennsylvania's first recovery center devoted exclusively to nurturing families and helping them heal from the impact of a loved one's substance use.

I am the founder/director of OASIS, and Ben's mom. My husband and I raised our boys in a neighborhood just a few miles away. I visited this house many times throughout Ben's childhood; with Ben in tow as a youngster when it housed a candle shop and in later years, I would bring our boys to feed the geese on the creek bank after school. Life was good. Never would our family have imagined the meaning this house would hold for us in years to come.

Like many youth, Ben dabbled with substances during his high school years. But Ben's substance use accelerated into a severe opioid use disorder, rendering him unable to complete his high school education or even hold a job. We reached out to many medical and mental health providers for help, but were met with ill-informed professionals who failed to understand how to treat and support youth with substance use disorders. Exasperated, we struggled to find support and resources for Ben and for us. Ben was ultimately treated inpatient eleven times, but it was never enough. For eight long and arduous years, I fought for my child's life, and nearly lost my own in the process.

On August 1, 2016, one week before his 24th birthday, Ben tragically lost his life to fentanyl poisoning. His death sent me spiraling into depression. I lost my sense of purpose and, due to the stigma of overdose death, lost relationships with many family, friends, and neighbors. Ben's addiction and subsequent death resulted in the breakdown of my social supports. Sadly, my experience is not unique.

After attending a protest march at Purdue Pharmaceuticals in August 2018, I found my purpose. My son is no longer here to speak up, so I am now his voice. As a result, our family founded the nonprofit Speak Up for Ben, Inc. Interestingly, the name B-E-N forms the acronym Break the silence, End the stigma, Never forget—and this is essentially our mission. Soon afterwards I approached our county and expressed the critical need that families have for education and support. The idea of a Recovery Community Organization addressing an unmet need in our community was met with great enthusiasm from our SCA. As a result, five years ago this month, we were awarded a contract from Northampton County Drug and Alcohol to open a family recovery center the first of its kind in Pennsylvania, and likely the nation.

OASIS provides a plethora of resources, and a comprehensive menu of evidence-based education, therapist-led counseling groups, wellness programs, and social supports. In addition to weekly programs, we organize many special activities including annual retreats and remembrance events. Utilizing a trauma-informed approach to care, we serve families with loved ones in active addiction, in recovery, and families of loss to addiction. We understand that addiction is a family disease, and believe in a holistic approach to healing the entire family system. If any family member breaks out of isolation and ends the cycle by working on their own recovery, then the person living with a substance use condition has the best possible chance of sustained recovery. We invite you to stop in! To learn more, visit us at https://oasisbethlehem.org.

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THE RASE project®

New policy of people-first language to replace 'smoker', 'vaper' 'tobacco user' and other behaviour-based labels

Marita Hefler ,[1,2] Sarah J Durkin ,[3] Joanna E Cohen ,[4] Lisa Henriksen ,[5] Richard O'Connor ,[6] Joaquin Barnoya,[7,8] Sarah E Hill ,[9,10] Ruth E Malone [11]

Tobacco Control has long recognised the power of language in defining and framing the commercial tobacco pandemic.[1] Language shapes our understanding of health behaviours, and the contexts in which they occur. As the tobacco control research field evolves, so too does our shared language. This helps the public health community to frame issues based on evidence, ensure precision and resist tobacco industry-preferred narratives in favour of more neutral terms,[2] as well as making visible to the public and policymakers the forces driving the tobacco pandemic. Perhaps most importantly, it highlights that the commercial tobacco pandemic is not merely the result of individual behaviour choices, but rather reflects systems failures by governments[1] which created and perpetuate exceptionalism for the tobacco industry, allowing it to continue to ply the deadliest trade in human history.

It is in this spirit that *Tobacco Control* is instituting a new policy of people-first language when referring to people who use tobacco and related products. Terms such as 'smoker', 'vaper' and 'tobacco user' (and their various iterations) should no longer be used as general descriptors. Henceforth, our author guidelines will specify placing people before product use for all tobacco and nicotine products. Guidance for, and examples of, appropriate terminology is included in the policy which can be viewed at: https://tobaccocontrol.bmj.com/pages/people-first-language-policy.

People-first language has been widely adopted in relation to people living with conditions such as HIV infection, diabetes, mental illness, epilepsy, obesity and substance use disorders. As highlighted by Goodwin and Walker,[3] continued use of the term 'smoker' in tobacco control lags other areas of public health, particularly substance use disorders, where terms such as 'alcoholic', 'drug abuser' and 'addict' have long been supplanted by terms that foreground people's humanity. Person-first language is specified in policy guidance by many professional organisations such as the American Medical Association[4] and some governments.[5 6]

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REDUCING STIGMA

Tobacco use shares characteristics with some of the conditions listed above, including experiences of stigma.[7 8] Denormalising the tobacco industry and use of its products is an essential element of tobacco control. However, it is important that the behaviour is decoupled from the person. A useful conceptualisation which has been proposed is that behaviour is malleable, while identity is (largely) immutable.[9] Labelling people as smokers or vapers suggests the behaviour is an immutable characteristic, an essential identity. When the behaviour is bound up in identity, it can become a target for overt discrimination.[9] Given how effectively smoking has been denormalised in many countries, assigning smoking as a personal attribute is inherently stigmatising. In jurisdictions with comprehensive tobacco control policies, smoker stigmatisation is such that 'smoker' is increasingly shorthand for a range of undesirable personal characteristics.[10] This is particularly salient given that smoking frequently intersects with other stigmatised identities,[11] class[12] and socioeconomic disadvantage,[13 14] and concerns about the role of stigma in creating and perpetuating smoking disparities.[15]

It is also important that most people who smoke started as children. Stigmatising people based on initiation of addictive product use before they had full understanding of the consequences or could consent is highly problematic. This labelling persists in marking and defining people by their smoking status even if they no longer use tobacco products (eg, ex-smoker or former smoker)[8] or have never done so (eg, non-smoker or never-smoker). In contrast, language which does not essentialise the behaviour opens the way for recovery, recognising that people often move along a spectrum of tobacco use.

COMMERCIAL DETERMINANTS OF HEALTH: RESISTING INDUSTRY NARRATIVES

Tobacco Control is concerned with the structural factors and policies that maintain or curtail the tobacco pandemic. The tobacco industry has long preferred to foreground individual behaviour,[16] obscuring the fact that 'smoker' identity is one which is manufactured for profit. It diverts a person from a life free from nicotine addiction to one of increased risk of disease and premature death. A person-first language policy contributes to subverting the power of corporate interests to foreground and reify individual behaviour as an essential and central component of individual identity. Tethering identity to a commercial product benefits the tobacco industry to the detriment of public health. If 'smoker' (or iterations thereof) is an inherent identity, it provides a basis for arguing against some tobacco control policies on the premise that smokers are subject to discrimination and other unfair treatment.

In countries with advanced tobacco control policies, the majority of people who smoke both regret starting and would like to stop.[17] However, the same is not necessarily true for people who use e-cigarettes, particularly given the diverse policy approaches and public attitudes to e-cigarettes globally. With knowledge of the potential harms of e-cigarette use in its infancy—particularly for people who have never smoked—public health should not reify identity-focused language around 'vaping'.

DESCRIPTIVE PRECISION AND ACCURACY

Apart from reducing stigma and countering the tobacco industry emphasis on individuals, the terms 'smoker', and increasingly 'vaper', are scientifically imprecise and lack universally agreed definitions[8] as well as direct equivalents between languages.[3] This is particularly problematic for e-cigarettes,

with the rapid changes in device types and contents.[2] People who use tobacco and nicotine products may not self-identify as smokers, vapers or 'users', an issue which has previously been noted particularly in relation to people who do not smoke daily.[18] This imprecision also applies to classifying people as 'former smokers',[8] as well as people who use other products.

Recommended language has implications for data collection and targeting tobacco-free efforts towards specific groups. Williamson *et al*[8] urge researchers and clinicians to use questions that target smoking behaviour, such as 'have you smoked, even a puff, in the past 30 days?' Similarly, they suggest avoiding questions that require adoption of a smoking identity such as 'are you a current smoker?' They also note that person-first terms can be used when categorising study participants according to current or previous smoking status (eg, 'people who never smoked' rather than 'never smokers', 'people who smoke every day' rather than 'daily smokers' and so on). We agree, and encourage all tobacco control researchers to consider using definitions and terms which apply these principles as a matter of good practice.

CHALLENGES

Implementing this policy will be challenging, and will take some time, not least because at *Tobacco Control*, we already have in the pipeline many accepted online-first papers using the terms smoker and/or vaper. Other papers in progress may have collected data using terms such as smoker, tobacco user, vaper or variations thereof. Copyeditors will need updated guidance. Authors will be anxious about word counts, but careful editing can address these issues. As Williamson *et al* note,[8] studies which explore 'smoker identity' may occasionally render use of the term unavoidable.

Changing social identity can play a role in smoking cessation pathways (Notley and Collins[19]) and identifying as a 'non-smoker' can be empowering and affirming. Conversely, some people who smoke and/or vape may wish to claim the identity of 'smoker' or 'vaper'. This may be seen as aligning with efforts by some groups to counter stigma and reclaim positive identities, such as movements to reverse fat-shaming, particularly for those for whom social exclusion risks entrenching their smoking identity.[20] However, people-first language does not invalidate how people may choose to self-identify. It provides a broader conceptualisation which reduces the potential for stigma, resists tobacco industry narratives and promotes greater precision and accuracy, as well as creating space which recognises these self-claimed identities can change.

CONCLUSION

Despite these challenges, we consider this is an important and necessary step. As authors and editors, we should not assume smoking status or other nicotine or tobacco product use as a primary or fixed identity. Our aim is to ensure the terms 'smoker', 'vaper' and 'tobacco user' will become rare in *Tobacco Control*. Humanity should always come before the interests of the commercial tobacco industry. Our language should reflect this.

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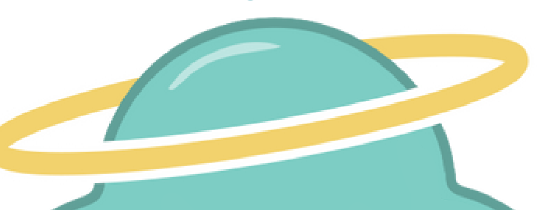

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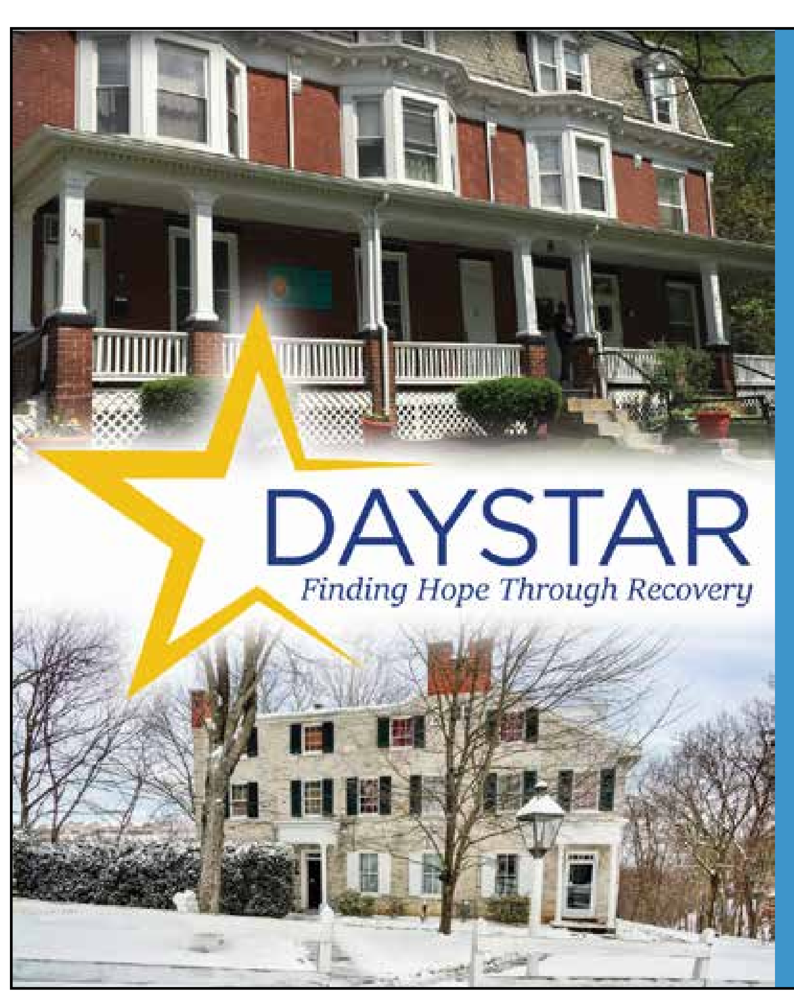

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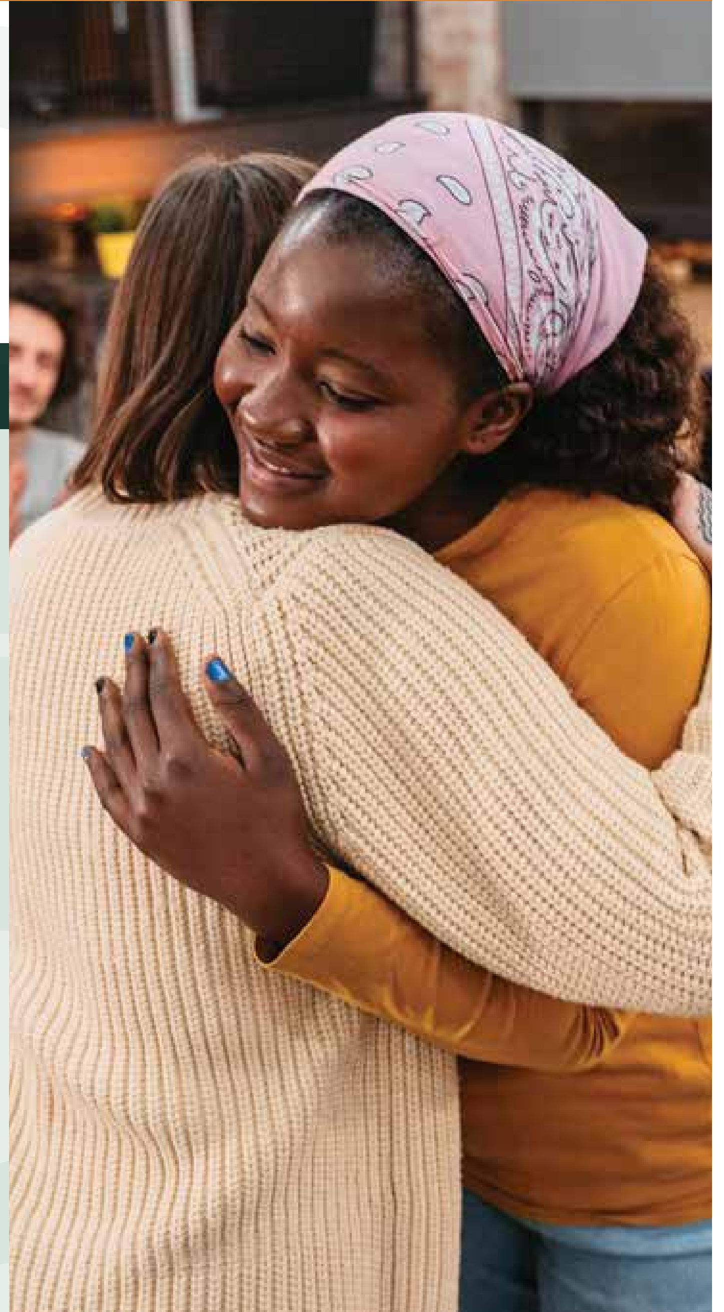

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