

The Danger of Misusing Prevention Data

Resisting Pathologization
and Hypersurveillance in
Behavioral Health Screenings
Through Trauma-Informed,
Community-Centered
Prevention Strategies

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SUMMARY

Behavioral health screenings, such as for adverse childhood experiences, are important data for identifying individuals and communities at risk of long-term ill health effects. However, without a framework that centers the desires and needs of the people who are screened and a trauma-informed lens, we risk pathologizing people and subjecting them to surveillance that can be harmful and intrusive. By carefully using prevention data to empower people to make decisions for themselves and their communities, we can enhance our care and public health through mutuality and collaboration.

WHO SHOULD USE THIS PAPER

- Primary care providers
- Behavioral health services
- Clinicians
- Health researchers
- Policymakers
- Community advocates
- Disability advocates

TAKEAWAYS & ACTION ITEMS

- Screenings to identify risk factors are important for the prevention of adverse health effects, but use of these data must resist pathologization and hypersurveillance, especially for people from marginalized communities.
- Using screening data to denote people or populations as “unhealthy,” “abnormal,” or “risky” or to surveil them beyond minimal and consented intervention is not only unethical and incorrect use of data, it is decidedly harmful and undoes the benefits of risk identification.
- Any screening data that point to health risks must be used as information to empower and equip individuals and communities to make decisions that best serve their desires, needs, and self-interest.
- With a trauma-informed framework, successful prevention strategies target systemic causes (e.g., racism, poverty, addiction, trauma, toxic stress, etc.) of such risk factors as adverse childhood experiences and lead exposure.
- Primary care and behavioral health providers must incorporate this framework to properly conduct, apply, and interpret prevention screenings. Policymakers should use it to create trauma-informed, community-centered policies aimed at preventing illness and promoting health.

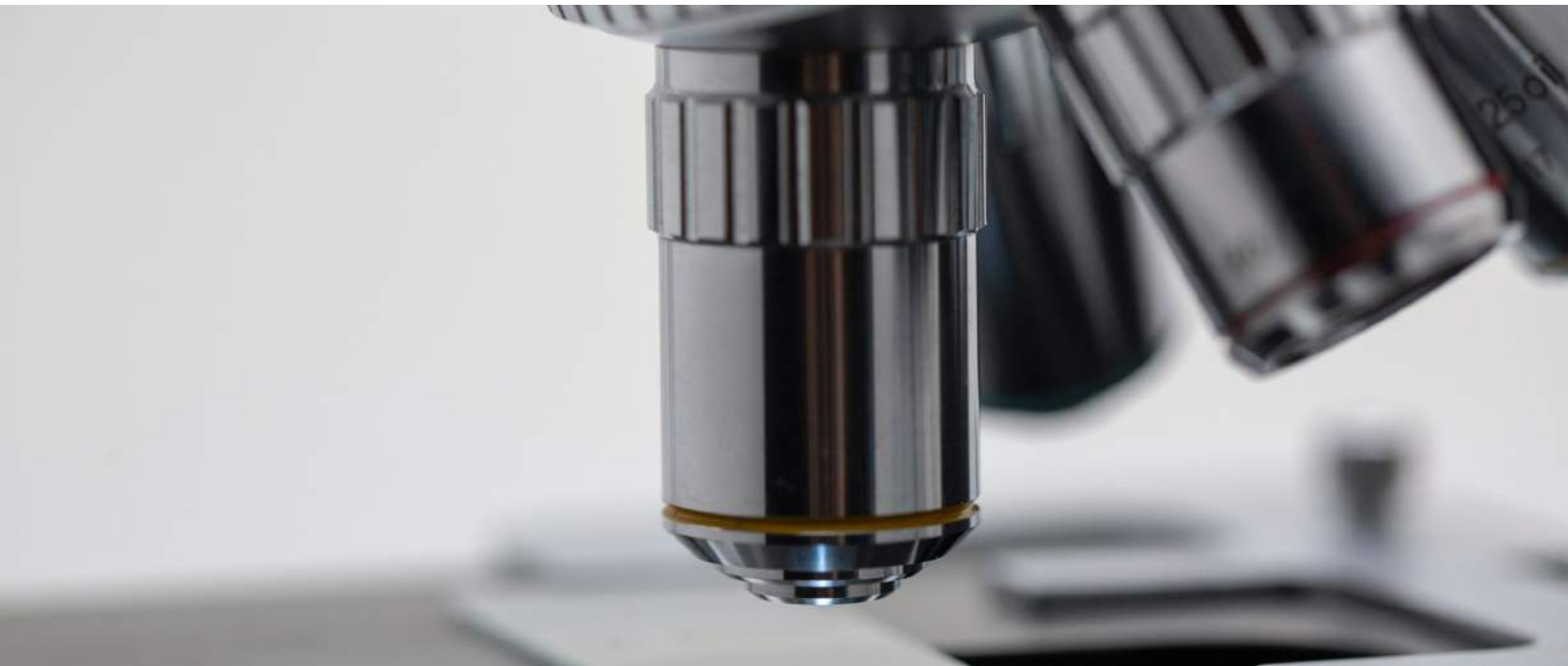
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Maic D'Agostino, *OhioGuidestone*



Introduction

Prevention is vital to healthcare, especially as it pertains to ensuring the health of entire communities through life-affirming public policies and practices.

However, identifying risk, especially individualized behavioral risk, can, if not interpreted and implemented properly, increase the dangers of pathologization (Fawcett, 2009; Winter et al., 2009; Beddoe, 2014; Hansen et al., 2014; Dej, 2016; Abrams et al., 2019; Essien, 2019; Barbosa & Leite, 2020; Fox et al., 2021), hypersurveillance (Armstrong, 1995; Fawcett, 2009; Burton-Jeangros, 2011; Saltes, 2013; Beddoe, 2014; Dube, 2018; Falabella, 2020; Patterson, 2021), prejudice such as anti-Blackness (McKeown et al., 2008; Tegnerowicz, 2018; Abrams et al., 2019; Essien, 2019; Elias & Paradies, 2021; Shonkoff et al., 2021), and other forms of manufactured (even if unwitting) harm that particularly affect historically marginalized, and overscrutinized, populations.

This certainly applies to risk factors for adverse health effects that care providers should and do screen for. Unfortunately, systems of discrimination — such as the many manifestations of racism, classism, ableism, sexism, xenophobia, homophobia, transphobia, and more — have poisoned the wells of good intention that public health prevention efforts draw from (Bowleg, 2012; Grollman, 2014; Bailey et al., 2017). This especially is true for children when health professionals attempt to identify risk for individuals’ future development of diseases, lower quality of life, and shortened life expectancy (Bartlett & Sacks, 2019; Shonkoff et al., 2021).

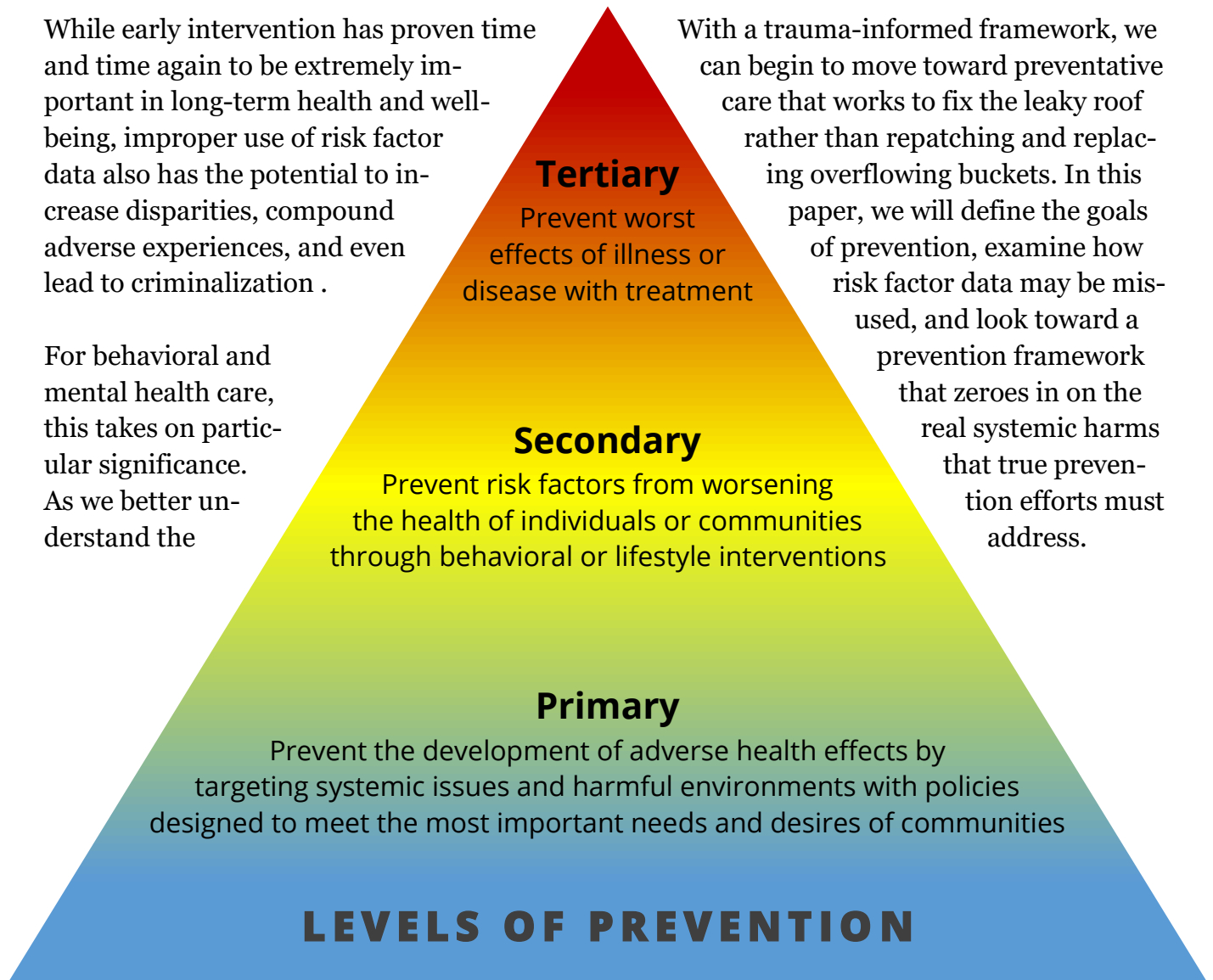
inextricable link between mental and physical health, the more we grasp how to prevent or at least respond to many disorders and diseases, beginning in childhood (Oral et al., 2016).

However, we have to approach our care, especially our preventative care, not as “improving” the individual or their health. Instead, care professionals, including psychosocial workers in behavioral health, should see themselves as equipping clients/patients with the tools and knowledge necessary for protecting themselves within the adverse social conditions they may find themselves in.

While early intervention has proven time and time again to be extremely important in long-term health and well-being, improper use of risk factor data also has the potential to increase disparities, compound adverse experiences, and even lead to criminalization .

For behavioral and mental health care, this takes on particular significance. As we better understand the

With a trauma-informed framework, we can begin to move toward preventative care that works to fix the leaky roof rather than repatching and replacing overflowing buckets. In this paper, we will define the goals of prevention, examine how risk factor data may be misused, and look toward a prevention framework that zeroes in on the real systemic harms that true prevention efforts must address.



About Prevention

Before we can discuss how prevention data can be misused, it is important to understand what we mean by “prevention.” To define prevention, we first have to know what we are trying to prevent.

For example, we (the medical community and society at large) want to prevent the development of heart diseases. Once we identify the problem — and ensure that it is in fact a problem — the next step is to try to interrupt that development. So we need to determine what causes heart disease. Unfortunately, this doesn’t have a clear answer, or even distinct answers. We quickly learn that many factors increase the likelihood of heart disease afflicting an individual. But how, where, when, and why this happens is difficult to figure out precisely, and so it’s hard to know to whom it actually will happen.

This makes prevention very much an inexact science. Far too often, in trying to apply risk assessment to an individual, we end up categorizing people into buckets they may never fall into (Bartlett & Sacks, 2019). And, even worse, we sometimes end up pathologizing individual/cultural behaviors or even individuals themselves based upon their identity rather than trying to eradicate the conditions that lead to the development of disease (Barker, 2010; Saltes, 2013).

Smoking is good example of this. Mass prevention efforts have caused people to associate “smoker” with “unhealthy person who will likely get lung cancer and die prematurely.” Smoking, however, is not

simply an individual choice a person makes in a vacuum. We know that nicotine is highly addictive. It makes the user feel good, especially if they are anxious or stressed. Smoking also is often (although not always) a social behavior. And research has demonstrated the power that advertising has had in reinforcing tobacco addiction (Benowitz, 2010).

In other words, asking people to stop smoking, without other supports, may improve many health outcomes, but it may harm others. Addicted smokers may need resources to manage their addiction, mental health care, and supportive social networks. Meanwhile, industry regulations, policies, and practices — not simply of the tobacco industry, but marketing in general — need to be scrutinized further. Neighborhoods where no nearby grocery stores exist (a.k.a. “food deserts”) but nicotinic products are readily available must receive investment in their accessibility to affordable, healthy, quality goods.

This is all to say that when our prevention message is “If you smoke, you are hurting your body” doesn’t always help. More importantly, this isn’t even the true issue and therefore does not have a clear, consistent, or fully beneficial effect. We tend to look at individuals as being “at risk” rather than seeing what in our social environments puts them at risk. But even when we do that, we tend to apply generalizations to individual experiences.

Prevention instead should be an act that the individual or community perform for

themselves, not the beneficent saviorism of clinicians and public health professionals descending from on high. We do not save lives; we care for people. Thus, by understanding this framework, we should not be screening individuals for risk factors to shield them from harm, but rather to notice which social risks they are exposed to and what types of care and support they might benefit from. This should be an informative practice for the patient or client, so that they can be properly equipped to

determine what they want to do about it, as should all healthcare decisions (Hannon, 2019).

Without this clarity of the purpose of prevention — i.e., to allow people to make decisions that best serve themselves and their self-interest long-term — preventative measures will fall the way of all forms of healthcare that fail to address systemic discrimination, inequity, and injustice: Doing as much as, if not more, harm than good.



Using ACEs, Lead Poisoning, and Other Prevention-Rich Data

We have strongly advocated for primary care screenings, especially in pediatric settings, for adverse childhood experiences (ACEs) (Pope, 2020), lead poisoning (Pope et al., 2020), and other social determinants and risk factors that affect long-term health, both physiological and psychological (D'Agostino, 2021; D'Agostino & Pope, 2021).

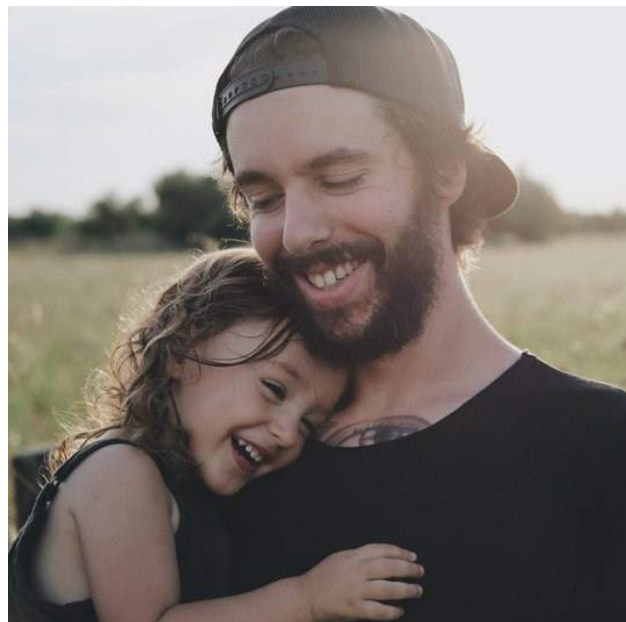
But we also recognize that these data do not tell us much about a particular individual and what their own unique outcomes may be. Yes, it's true that the more ACEs a person has, the more they are in danger of developing serious illnesses, mental and physical, later in life (Oral et al., 2016; Pope, 2020). However, we also know two important facets of ACEs: First,

these experiences are almost always due to systemic issues (poverty, racism, abuse, violence, incarceration, substance use disorders, lack of proper healthcare); and secondly, they are compounded by social structures that marginalize or penalize people with these lived experiences.

A child growing up in a low-income, single-parent household — with an incarcerated parent, living in unsafe housing, and lacking the same level of protection against adult abuse that children from wealthy families have — is not at risk because of their family structure. Instead, it is our systemic failure to support families like theirs, to design our society around them — as much as it's designed around the white middle-to-upper-class child in a two-parent, suburban household — that puts the child in harm's way.

This understanding is, for obvious reasons, central to effective prevention efforts. If we are trying to prevent single-parent households, then our preventative strategies will not just fail, they will crash and burn, taking families and children down with them. If, instead, we are trying to prevent the socially manufactured adversity that single parents and children from single-parent households must deal with, then we may see success.

These basic principles are true for other prevention screenings as well. If a child has an elevated blood lead level, our intervention must not be to “prevent” the child from behavioral issues, lower test scores in school, or otherwise burden them with societal expectations of “normal.” In contrast, what we must do is prevent lead poisoning, which is a systemic issue; build our interventions and treatments around these children and their families, based on what they decide



they need and want; and restructure our child services and education systems to be more expansive and inclusive in their care rather than trying to make children conform to a particular behavioral structure.

Even our growing understanding of biologically based effects, such as epigenetics, can lead down the paradoxically linked paths of victimization and victim blaming. As our knowledge of and ability to track epigenetic modifications increase, we must recognize that these effects tell us nothing about who a person is or where they come from or what will happen to them. Instead, they give the client/patient and the provider/professional information and tools to work together to decide on a course of action.

All of these related but myriad considerations need to be accomplished in conjunction in order to adequately address the underlying issues. This is the real preventative work. Certainly, it is much easier said than done. What does “restructure systems” even mean, in practice? For starters, it means acknowledging the systems themselves and then addressing each input, each facet, each node of the system.

Resisting Inequitable Systems, Building Equitable Ones

When we see disparate effect sizes in prevention programs or policies for various subsets of demography — e.g., worse outcomes for Black, Indigenous, Latinx, impoverished, rural, disabled, nonbinary, or otherwise marginalized people — we know that the cause is systemic inequity and injustice, not simply in society as a whole but specifically in the application of prevention strategies.

It is not the identities of the individuals in these populations and communities that put them at risk of being harmed by usually well-meaning preventative measures. Instead, the real danger lies in inequities:

- How our programs and policies are designed;
- What characteristics we consider to be “standard,” “normal,” or “healthy”;
- Our interpretation of data, particularly quantitative data;
- And our (likely subconscious) desire to gain social cachet through services imparted in a top-down model rather than approaching care and public health as fully collaborative and based upon mutuality.

To counter this, we must insist on interpretation of data that includes the populations to whom the data belong. Obviously, we

should not abandon high-level, upstream prevention efforts. Rather, we should:

1. Create assessments that are relevant to the people being assessed;
2. Resist suggesting certain outcomes apply to people whose screenings uncover particular markers or risk factors;
3. Determine courses of action that are based around the desires of the individual, their family, and their community;
4. And use the data we collect to address societal issues.

“If you have come here to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together.”

Lilla Watson

Some of this might seem simple or common sense, but when the machines of efficiency begin grinding, they often end up destroying more than they build. We can lose the focal point on relational health — i.e., the importance of relationships in care — if we see ourselves as doing good for an individual or community rather than with them. As Gangulu educator and activist Lilla Watson said, “If you have come here to help me, you are wasting your time ... But if you have come because your liberation is bound up with mine, then let us work together” (Watson, 2007).

If we tell a community that they need a new road so that they can get to where they need to go but we uproot an old grove of beloved trees to make way, does that truly

benefit the community? What if, instead, we gave a community the opportunity to design their own access? To do that, a community needs to know what it wants; how it wants to obtain what it wants; and what it needs to achieve those goals. As service providers, researchers, health care workers, and so on, our job in this is to help communities break down the barriers that prevent them from accessing what they need and want: their own brand of health, well-being, and joy.

The principles of trauma-informed care can be instructive here (Oral et al., 2016; Dube, 2018; Earls, 2018). When we take a trauma-informed focus on systemic issues, collaborative healing, empowerment, relational health, and trust, we can see how prevention data — individual or communal — may

tell us more about the conditions that cause adversity, toxic stress, and trauma than a prognostication of an individual's health outcomes. Likewise, with a trauma-informed framework, we can move from a model making individuals responsible for the causation of their own health issues and reliant on care providers to fix them to instead a model of giving individuals tools and knowledge that can help them live in, grow in, and even change their environments — and, if necessary and desired, their behaviors.

Building new systems takes time, effort, money, willpower, commitment, and trust. And, above all, it takes communities coming together to decide what's best for themselves, affirming the life, well-being, and dignity of each person in the community.

FOCUS ON STRENGTHS, NOT DEFICIENCIES

While ACEs understandably have captured headlines, empathetic hearts, and the eyes of policymakers, many researchers have begun delving into the other side of childhood experiences: the good things that have happened in a child's life.

Referred to either as benevolent or positive childhood experiences (BCEs and PCEs, respectively), studies are showing that these experiences — which are not absent in children with high ACE scores — seem to have the opposite effect that ACEs do, independent of any negative effects.

Early evidence shows that actively encouraging and centering PCEs in childhood could help prevent the development of depression and other mental health issues in adulthood, as well as positively affecting relational health as a person grows up (Bethell et al., 2019). Higher BCE scores likewise seem to indicate that these experiences function as a protective factor from distress, including with homeless parents even though the systemic, societal harms of homelessness are still present in their lives (Merrick et al., 2019).

This research reveals to us what many underprivileged yet resilient communities already know:

1. People aren't defined by the harm done to them; and
2. Inner strengths that create joy and connectedness in the self and the community should be encouraged, promoted, and celebrated in the provision of health and human services.

Focusing on these facts helps move us as healthcare providers from a care framework of fixing problems to one of enhancing lives.

Conclusion

Screenings for major lifetime risk factors, such as adverse childhood experiences, are vital in healthcare, beginning in pediatric primary care settings. But these screenings must be used as tools for the individual, family, and affected communities, not prediagnostic warning labels. They also should, in aggregate, inform our social policies to create more supportive, affirming systems.

Thus, we must resist the temptation to pathologize (“What is wrong with you”) or surveil (“What will be wrong with you”) the individual. Instead, we must focus together — as care worker and client, public health professional and community, policymaker and citizen — on the systemic issues of harm (“What happened to you”) and a strengths-based prevention plan (“What is already in you”), while avoiding the pitfalls of stereotyping and pathologizing strength as well (Abrams et al., 2019).

This framework stems from trauma-informed practices, as well as other forms of care that try to be sensitive to the diverse experiences and backgrounds of the people we serve. We can’t take shortcuts to better health, whether it is the health of an individual or entire populations. This is true for prevention as much as it is for treatment. And so we must reject simplified conclusions, particularly when they place the blame for ill health, chronic disease, mental illness, addiction, etc. on the individual, demographic group, or community instead of on the social systems that cause and allow these issues to fester.

True healthcare is allying ourselves to the people we serve. We must give people the tools and knowledge they need, so that they can forge their own paths: to a place of healing when they’ve been hurt; and, when they are put in harm’s way, to a space of safety, protection, and care.



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