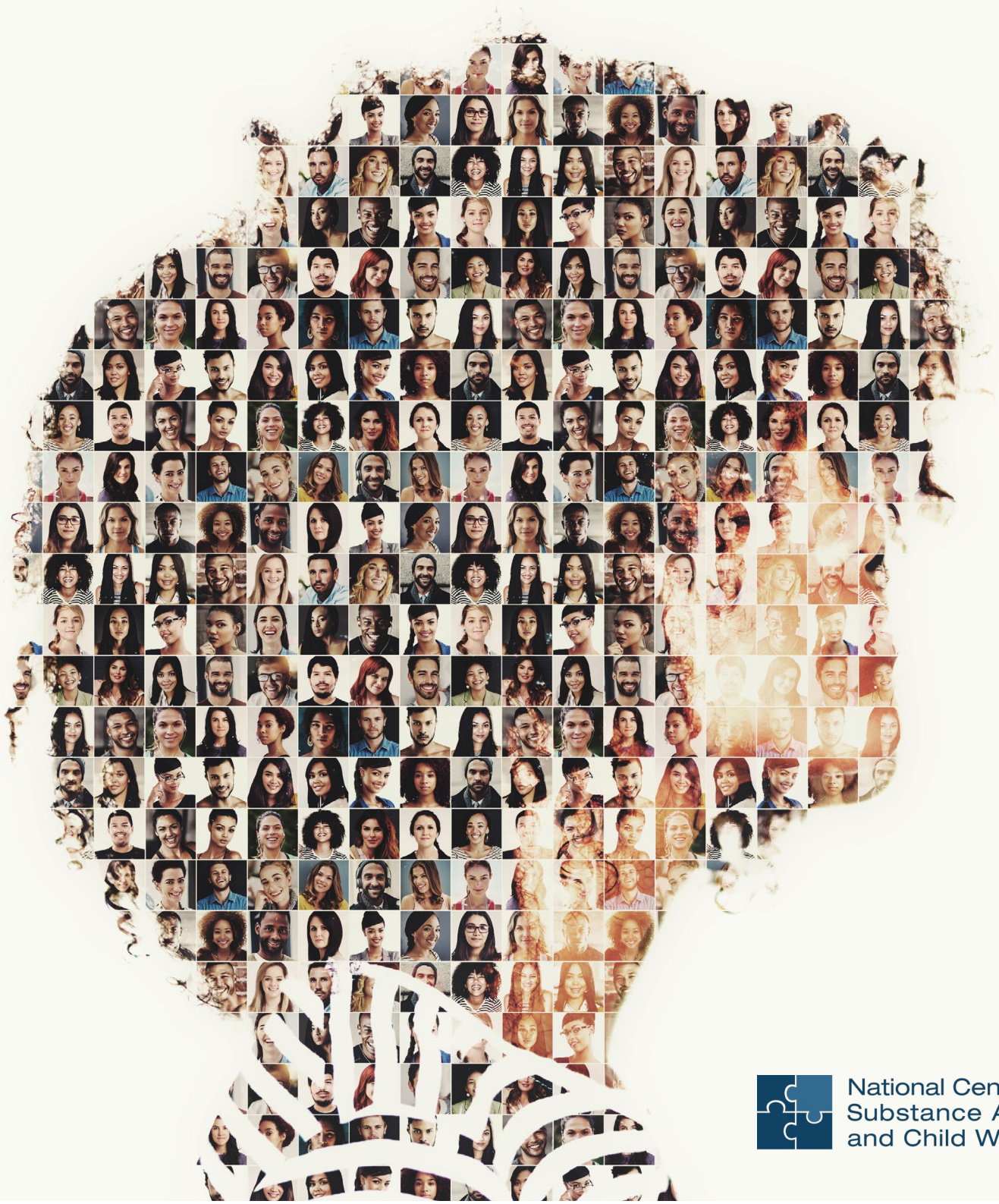
DISRUPTING STIGMA:

How Understanding, Empathy, and Connection Can Improve Outcomes for Families Affected by Substance Use and Mental Disorders



National Center on Substance Abuse and Child Welfare

STIGMA ATTACHED TO SUBSTANCE USE AND MENTAL DISORDERS CAN DRIVE AWAY THE VERY PARENTS AND FAMILIES WE SEEK TO SERVE.

Stigma specifically related to child abuse, neglect, and prenatal substance exposure affects the attitudes of healthcare and treatment professionals; child welfare and court professionals; social service agencies and workers; as well as family, friends, and most notably, the person with the substance use and/or mental disorder.

Not only can negative attitudes create barriers for parents seeking help, but they can also exacerbate existing disparities in treatment services and outcomes for Black, Indigenous, and People of Color (BIPOC), the LGBTQ community, individuals living in poverty, and other underserved groups. If left uncorrected, misperceptions and misinformation about substance use disorders (SUDs) can also lead to discrimination. Disrupting stigma requires practitioners to understand: 1) the factors that create and perpetuate it; 2) the history of stigma related to individuals affected by SUDs; and 3) stigma's detrimental effects on children, parents, and family members.

The National Center on Substance Abuse and Child Welfare (NCSACW) prepared this brief to support cross-system collaborative teams in their work to reduce stigma in interactions, expectations, and policies affecting families. This brief provides several strategies, including how to intentionally use language to: 1) fight stigma and 2) facilitate engagement with parents and family members affected by SUDs. Information contained here stems from best practices in the field—gleaned from experience working with relevant partners across the country—and a thorough review of literature and materials cited from expert sources, such as the Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), Office of Juvenile Justice and Delinquency Prevention (OJJDP), National Association of Drug Court Professionals (NADCP), and the Recovery Research Institute. For more information, see the bolded terms throughout the brief that include links to tools and resources that delve deeper into each topic.

WHAT IS STIGMA?

STIGMA IS DEFINED AS THE RELATIONSHIP BETWEEN AN ATTRIBUTE — SUCH AS DRUG USE — AND A STEREOTYPE THAT ASSIGNS UNDESIRABLE LABELS, QUALITIES, AND BEHAVIORS TO A PERSON EXHIBITING THE ATTRIBUTE.

Stigma exists on three different levels.[1,2,3,4,5,6,7,8]

STRUCTURAL STIGMA

Also known as institutional stigma, structural stigma includes laws, policies, or regulations that can both intentionally and unintentionally result in discrimination. This type of stigma can limit the opportunities, resources, and well-being of the stigmatized group. An example of structural stigma is a program policy prohibiting individuals from using particular forms of prescribed medication for addiction treatment. It is important to note that restrictive medication-assisted treatment (MAT) policies could violate federal disability rights protections under the Americans with Disabilities Act.

PUBLIC STIGMA

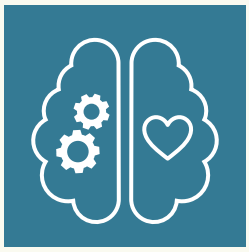
Public stigma refers to attitudes, beliefs, and behaviors of individuals and groups. This happens when stereotypes produce an emotional reaction or prejudice that results in discrimination. In the case of substance use, stereotypes often portray individuals as *choosing* to use alcohol or other drugs—and therefore deserving blame for their substance use or addiction—rather than being *affected by* a chronic health condition.

SELF-STIGMA

Also known as shame, self-stigma results from individuals internalizing negative stereotypes. It is also possible that the very people (including family members and agency professionals) meant to help only *add* to the shame. For example, the use of terms such as “clean” and “dirty” when referring to drug test results can perpetuate stigma. Shame, for individuals affected by SUDs, leads to feeling flawed: unworthy of love, belonging, and connection. Shame may also deter a person from seeking help.

HOW DOES STIGMA DEVELOP?

THOUGHTS & BELIEFS



EMOTIONS & FEELINGS

BEHAVIORS & ACTIONS

MEDIA PORTRAYALS CAN EITHER CREATE AND PERPETUATE STIGMA OR WORK TO ELIMINATE IT.

The media can shape a person's understanding of substance use and mental disorders while attempting to explain how these conditions affect individuals and family systems. Unfortunately, many mainstream media accounts of those affected by SUDs perpetuate negative stereotypes—painting misperceptions and fueling the spread of misinformation.[9,10,11] Professionals lacking adequate training and education, along with family members and friends, and even the affected individuals themselves can reinforce these inaccuracies.

A lack of personal or direct experience with individuals affected by SUDs can perpetuate stigma further. This lack of experience can create a narrative about all members in a group; for example, seeing *others* as a subgroup and *people like us* as individuals. The act of "othering" commonly occurs when individuals say or think "those people" rather than understanding that substance use and mental disorders are quite common.[12] An estimated one in four individuals in the U.S. will experience mental health or substance use problems during their lifetime.[13] Roughly 51.5 million U.S. adults reported a mental illness in 2019, while approximately 19 million people ages 18 and older reported having a SUD.[14]

Two additional factors that contribute to stigma placed on a particular disease or disorder include perceived control over the condition and perceived fault in acquiring the condition.[15] Regarding stigma and SUDs, a common misconception is that drug dependence is a choice, which assumes the person has control over the condition and is to blame. Yet research shows that complex interactions of the body and mind—particularly when introduced and exacerbated by stress and trauma, inherited traits, adverse childhood experiences, and social environments—all combine to increase the likelihood of developing a chronic health condition—whether a SUD, obesity, or high blood pressure.[16] The combination of these factors contributes to an individual's thoughts and beliefs about SUDs, which affect emotions, feelings, and in turn, behaviors and actions.

HISTORY OF SUBSTANCE USE STIGMA IN U.S. DRUG POLICIES

ONE CAN GENERALLY CATEGORIZE AMERICA'S DRUG POLICIES ALONG TWO DIFFERENT TRACKS—EITHER CRIMINAL JUSTICE (E.G., PREDOMINANTLY PUNITIVE LAWS AND INCARCERATION) OR MEDICAL CARE (E.G., MEDICATION ASSISTED TREATMENT).

Responses to multiple drug epidemics throughout history reflect these policies. For example, in the 1970s drug abuse was referred to as "America's public enemy." This contributed to a policy approach referred to as a "War on Drugs" with increased penalties for possession and sales of drugs, disproportionately affecting low-income communities and people of color—particularly the Black/African American population. The policies had devastating effects on these families and communities lasting for generations.[17] The negative views of substance use continued to steer other anti-drug campaigns such as "Just Say No" in the 1980s and influenced responses to the crack cocaine epidemic that spawned increased penalties, policing, and imprisonment.[18] Negative media portrayals were common during this time—for example, incorrectly labeling infants exposed to substances as "addicted" and referring to them as "victims"—which further perpetuated damaging stereotypes, stigma, and discrimination.

The Affordable Care Act that requires substance use disorder and mental health treatment as essential benefits in health plans contributed to promoting a health care response to the current opioid crisis. The health care system's response to persons with opioid use disorders has also been driven by the availability of medications for opioid use disorders that are provided in health care settings.[19] Despite progress in reducing stigma, policymakers, practitioners, the media and public all have a role to play to reduce harmful effects of stigma on families who are affected by substance use and mental disorders.

HARMFUL EFFECTS OF STIGMA

SUBSTANCE USE, MENTAL HEALTH DISORDERS, AND CHILD ABUSE AND NEGLECT ARE THREE OF THE MOST HIGHLY STIGMATIZED CONDITIONS IN SOCIETY.[20]

Stigma and shame associated with substance use and mental disorders as well as child welfare involvement 1) result in a reduced chance that the individual will seek treatment; 2) influence the kinds of treatment people are willing to accept; and 3) affect treatment retention as well as the individual's ability to maintain a recovery-oriented lifestyle.

Stigma can specifically

- Exacerbate trauma common among people with SUDs, as well as historical trauma experienced by BIPOC
- Create fears of having children placed in out-of-home care if parents admit to having a SUD, which is compounded for BIPOC who may have experienced disproportionate surveillance, legal consequences, and child welfare involvement
- Contribute to disparities accessing and completing treatment for BIPOC, LGBTQ, and other underserved groups[21,22,23]

In addition, stigma reduces the likelihood that children and other family members will have access to services and supports. For example, stigma can

- Disrupt infant bonding and parent-child attachment
- Interfere with supporting birth parents to care for their infant if there are concerns about substance use
- Discourage school-aged children from reaching out for support
- Lead children to blame themselves for a parent's SUD
- Contribute to children's ongoing mental health, educational, and attachment challenges
- Affect how adolescents and young adults view their parent's SUD which can, in turn, influence their own development of a SUD[24,25,26,27,28]

Practitioners and services providers have many opportunities to reduce the stigma families experience.

RETHINKING RESPONSES AND APPROACHES

INDIVIDUALS' BELIEFS AFFECT BEHAVIOR, SO WHAT IS BELIEVED ABOUT FAMILIES AFFECTED BY SUDs INFLUENCES RESPONSES TO THEIR NEEDS.

Professionals' beliefs, experiences and expectations affect the way parents progress in treatment and recovery, ultimately influencing family well-being. These thoughts also affect how administrators structure programs and policies for families. Thus, providing education on these topics is critical, specifically on the brain science of SUDs and the relationship between trauma and SUDs. Understanding the stages of change also helps professionals learn how to adjust their expectations and tailor interventions to families' needs.[29,30] Techniques such as Motivational Interviewing support successful SUD treatment and recovery by helping parents resolve ambivalence and strengthen their commitment to change.[31]

The language practitioners use and how they talk to parents and families affect the ability to engage them into treatment services. Using person-first, strengths-based language helps reduce the stigma and bias associated with substance use (see *Spotlight Strategy: Language Does Matter on page 10*).

Additionally, responding to parents with empathy and connection can help them engage in the work of recovery and *reconnection* to their children, support systems, and community. Empathy begins by examining and acknowledging one's own attitudes and biases. It is critical for practitioners to examine their own biases about parenting, substance use and mental health recovery, the roles of mothers and fathers, the cultures of people from different races and ethnicities, poverty, and any number of other potentially stigmatized attributes.[32,33,34]

THE STAGES OF CHANGE

Precontemplation	Contemplation	Preparation	Action	Maintenance
The parent is not considering change, is aware of few negative consequences, and is unlikely to act soon.	The parent is aware of some pros and cons of substance use but feels ambivalent about change. The parent has not yet decided to commit to change.	The parent has decided to change and begins to plan steps toward recovery.	The parent tries new behaviors, but these are not yet stable.	The parent establishes new behaviors on a long-term basis.

SOURCES: Center for Substance Abuse Treatment, 1999; Prochaska & DiClemente, 1984

Working with peer supports, such as recovery support specialists, who are experienced and trained in recovery also helps professionals better understand the unique needs of families affected by substance use and mental disorders. Peer supports help facilitate connection—a critical part of recovery—instill a message of hope, and convey the healing message that parents are not alone.[35] Another primary strength of peer supports is their ability to communicate with empathy in their work with families.

Acknowledging the unique lived experiences of children, parents, and family members plays an important role in this work. For example, it remains critical to recognize the identities of individuals, such as race, ethnicity, gender, sexual orientation, socioeconomic status, education, and disability. Individuals may experience accumulated distress from these intersecting, stigmatized attributes that produce trauma and shame; this feeling only increases the likelihood of developing a mental health or substance use disorder.[36,37]

It is also important to consider the presence of co-occurring conditions, which can exacerbate challenges in access to services and ongoing recovery support. Individuals affected by SUDs may also experience challenges with trauma, intimate partner violence, and mental health such as eating disorders. In their work with families, practitioners need to consider how an individual's unique lived experience contributes to outcomes, taking into account their strengths and needs. For example, studies of substance use and mental disorders revealed members of racial, ethnic, and other groups, such as the LGBTQ community, are less likely than their white heteronormative counterparts to 1) receive appropriate diagnoses; 2) enter, remain in, and complete treatment; 3) receive adequate care; and 4) report satisfaction with treatment.[38,39,40,41,42]

Approaching the work with these key considerations in mind helps practitioners respond effectively to the complex needs of individuals and places them in a unique position to reduce stigma.

STRATEGIES FOR DISRUPTING STIGMA

OVERCOMING STIGMA IMPROVES OPPORTUNITIES, ACCESS, AND RESOURCES FOR FAMILIES AFFECTED BY SUDs.

Efforts to disrupt stigma can happen at all levels—from administrators who structure programs and set policies to frontline staff in their interactions with families. There are several ways to move from stigma to inclusivity, including strategies for agencies to become more trauma informed, family centered, and recovery friendly.

ORGANIZATIONS CAN

- **Recognize SUDs as a chronic disease and brain disorder, and reflect this understanding in language, responses, and policies:** It is important to understand that "return to use" can be part of having a SUD, and sometimes it happens during the SUD treatment and recovery process.
- **Debunk common myths:** Misconceptions such as "MAT is substituting one drug for another" or "parents love their drugs more than their kids" are harmful to families and perpetuate stigma and discrimination.
- **Understand and value data about access, treatment, and recovery:** Examples include disaggregating data and examining issues related to disproportionality and disparity in outcomes.
- **Integrate peers and recovery specialists into their service delivery and work with families:** Ensuring that peers have sufficient training and support is critical.
- **Provide training, education, and ongoing support to staff and collaborative partners:** It is essential to also include practice or coaching lessons, such as role play, to help staff master new skills and equip them with the tools needed to better support families. As a starting point, organizations can use tools like the *Collaborative Values Inventory* to assess how much a collaborative group or partnership shares beliefs and values that underlie its work.
- **Identify stigma in interactions, expectations, language, and policies:** One strategy is to confront bias and stigma in discussions with parents, collaborators, partners, and supervisors. The *Building Collaborative Capacity Series* describes ways to create collaborative teams, communication protocols, and practice innovations. Another strategy is to examine pictures, posters, and written materials in spaces where interactions with families take place to ensure that they demonstrate inclusivity. Organizations can conduct a systems walkthrough (a systematic review of agency-specific and cross-system practices), or a trauma-responsive assessment, such as a trauma walkthrough, to better understand the experience through the parents' eyes.[43,44]

PRACTITIONERS CAN

- **Use a strengths-based perspective and focus on what is going well:** Celebrating achievements as they occur encourages parents to continue making progress in their treatment and recovery.
- **Listen to clients and remain patient during the process of recovery:** Understanding and responding to parents' unique needs helps them successfully engage in treatment and achieve stable recovery.
- **Understand there are different responses to self-stigma or shame:** Responses may include withdrawing, lashing out, or seeking perfection. Knowing this helps individuals work through their self-stigma and practitioners cultivate empathy and connection with parents.[45]
- **Honor the individual's role as a parent and the child's attachment to the parent:** Promoting the value of stronger parenting skills and parent-child relationships helps improve overall family well-being through a family-centered approach.
- **Make mindful language choices and recognize that words have power:** The shift from using identity-first (drug abuser) to person-first (parent with a SUD) language demonstrates individuals have a "treatable" problem and their disorder does not define them.

SPOTLIGHT STRATEGY: LANGUAGE DOES MATTER

Language is a key mechanism to either uplift and empower families or exacerbate their sense of hopelessness and stigma. In the case of substance use, language changes over time as the field gains a better understanding of SUDs and the powerful effect of words. Yet even today the use of pejorative language persists when describing individuals affected by SUDs. This stigmatizing language reinforces negative beliefs and stereotypes.[46]

The language used—and how practitioners talk to parents and family members—affects a family's ability to connect with others, engage in treatment services, and ultimately achieve improved outcomes. The use of person-first, strengths-based language, which puts the person before any diagnosis and focuses on their innate capacities, helps reduce stigma and bias associated with substance use. A training resource available from SAMHSA's Center for the Application of Prevention Technologies (2017) examines the role of language in perpetuating stigma and offers tips for avoiding stigmatizing language. The following are examples of language choices to reflect the understanding of SUD as a disease.[47]

Instead of…	Try…
Addict or drug abuser	Person or parent with a substance use disorder
Clean or dirty drug screen	Screen tested positive or negative for substances
Former addict	Person in recovery
Opioid replacement	Medication-assisted treatment or medication for opioid use disorder
Drug-addicted baby	Infant prenatally exposed to substances
Drug of choice	Drug of use
Relapse	Return to use

> "Research shows that the language we use to describe this disease can either perpetuate or overcome the stereotypes, prejudice, and lack of empathy that keep people from getting the treatment they need."
>
> - MICHAEL BOTTICELLI, FORMER DIRECTOR OF THE OFFICE OF NATIONAL DRUG CONTROL POLICY[48]

The Recovery Research Institute provides an online tool called the Addictionary that has an extensive listing of person-first, strengths-based language options for individuals and teams.

Being intentional with language is a simple first step. Practitioners can begin using appropriate language, modeling it for colleagues and partners, and then repeating it when faced with inappropriate language. Organizations can adopt new ways of talking about families, themselves, and their systems; they can formalize these changes in written guidance. Developing a shared agreement or memorandum of understanding with key partners about using appropriate language when describing children, parents, and families can reduce stigma and improve cross-systems collaboration.

ADDITIONAL RESOURCES FOR DISRUPTING STIGMA

Practitioners and community partners can use the following resources to support their efforts to disrupt stigma:

- *The NCSACW Online Training Tutorials* help professionals increase their knowledge and skills to work with families affected by SUDs while also building cross-systems collaboration across the various agencies serving them.
- *Putting the Pieces Together: Disrupting Stigma to Support Meaningful Change for Families in Family Treatment Court* is a course for family treatment court teams and practitioners; it provides information on stigma related to parenting and SUDs, and a framework for dismantling practices that do not benefit all families.
- *Language Matters: Disrupting Stigma to Support Meaningful Change for Families*, recorded during the 22nd National Conference on Child Abuse and Neglect in 2021, teaches child welfare agencies and community providers to identify and disrupt stigma in interactions, expectations, language, and policies affecting families.

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National Center on Substance Abuse and Child Welfare

Children's Bureau
An Office of the Administration for Children & Families

SAMHSA
Substance Abuse and Mental Health Services Administration

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