State-Level Eating Disorder Prevention and Surveillance:

Current Initiatives and Ways to Take Action

July 18, 2024

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Strategic Training Initiative for the Prevention of Eating Disorders

Eating Disorder Public Health Surveillance Working Group

Eating Disorder Public Health Surveillance Working Group

- Interdisciplinary, multi-state group comprised of public health professionals and researchers specializing in eating disorders
  - Members from Alaska, Arizona, Kentucky, Massachusetts, Vermont …
- Mission: To advance the surveillance of eating disorders in the U.S.
  - Ensure the routine collection of high-quality data on eating disorders
  - Use available data to inform treatment, prevention, and equity efforts
- **Priority focus**: Surveillance via the Centers for Disease Control and Prevention (CDC)'s Youth Risk Behavior Survey (YRBS)

Speakers

Ariel Beccia, PhD
Boston Children's Hospital

Haley McGowan, DO
VT Dept. of Mental Health

Brittany Celebrano, RDN
AZ Dept. of Health Services

Eating disorders are a growing public health threat for adolescents living in the U.S.

Eating disorders are **common**

Eating disorders are **deadly**

Eating disorders are **costly**

Streatfield et al., 2021; van Hoeken et al., 2020; Ward et al., 2019

SOCIAL & ECONOMIC COST OF EATING DISORDERS IN THE UNITED STATES

Report by the Strategic Training Initiative for the Prevention of Eating Disorders, Academy for Eating Disorders, and Deloitte Access Economics

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AED Academy for Eating Disorders

COST TO ECONOMY & SOCIETY

$64.7 Billion } Yearly economic cost of eating disorders

Additional loss of wellbeing per year { **$326.5 Billion**

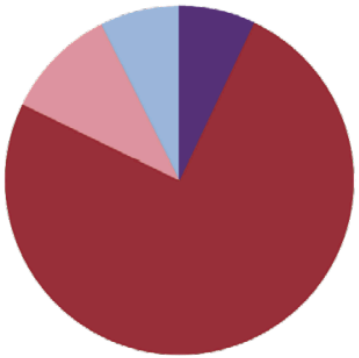
Cost Breakdown:

Productivity Losses ($48.6B)

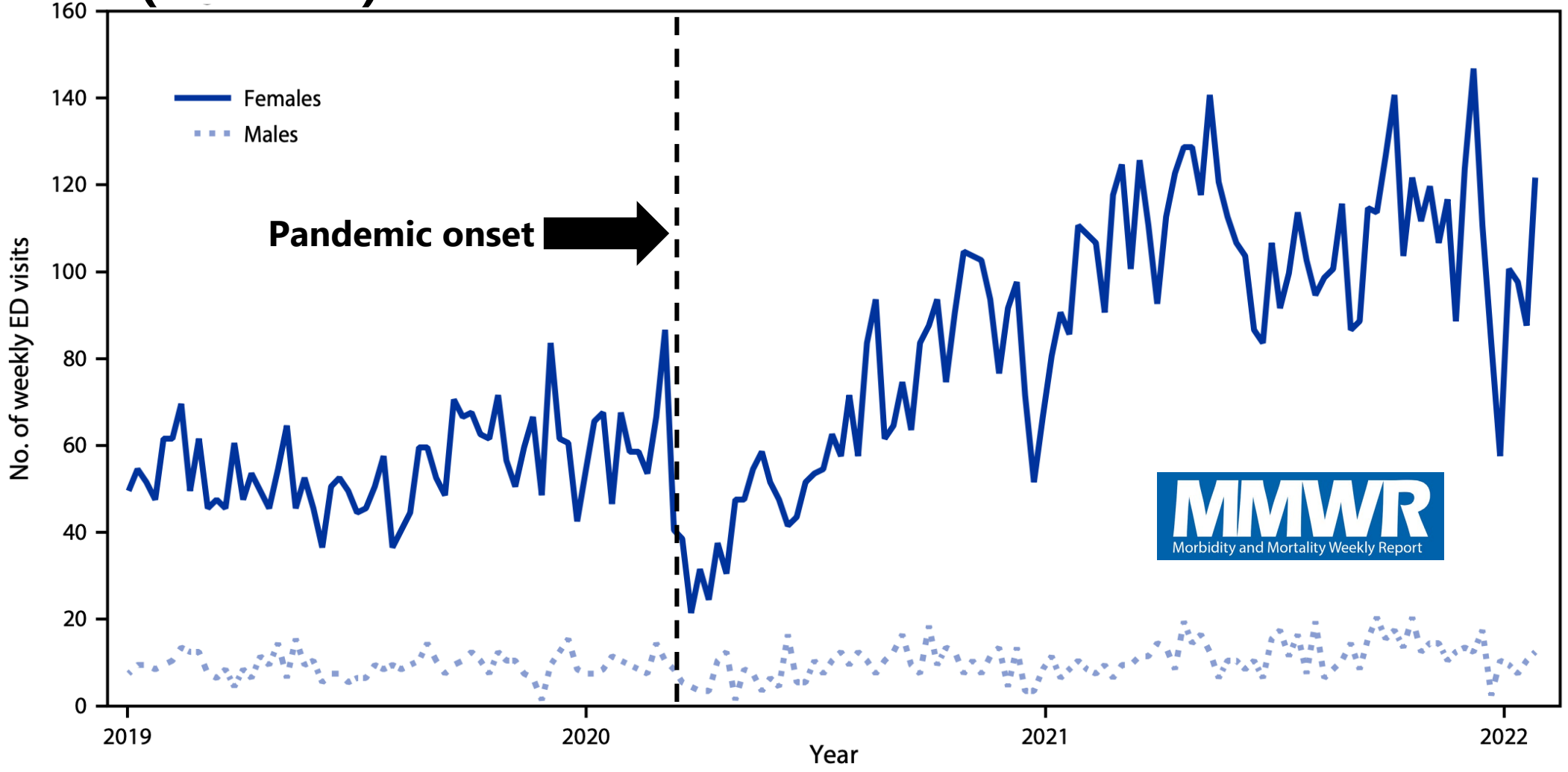
Informal Care ($6.7B)

Efficiency Losses ($4.8B)

Health System ($4.6B)



Weekly number of emergency department visits associated with eating disorders among adolescents aged 12–17 years, United States (2019–22)



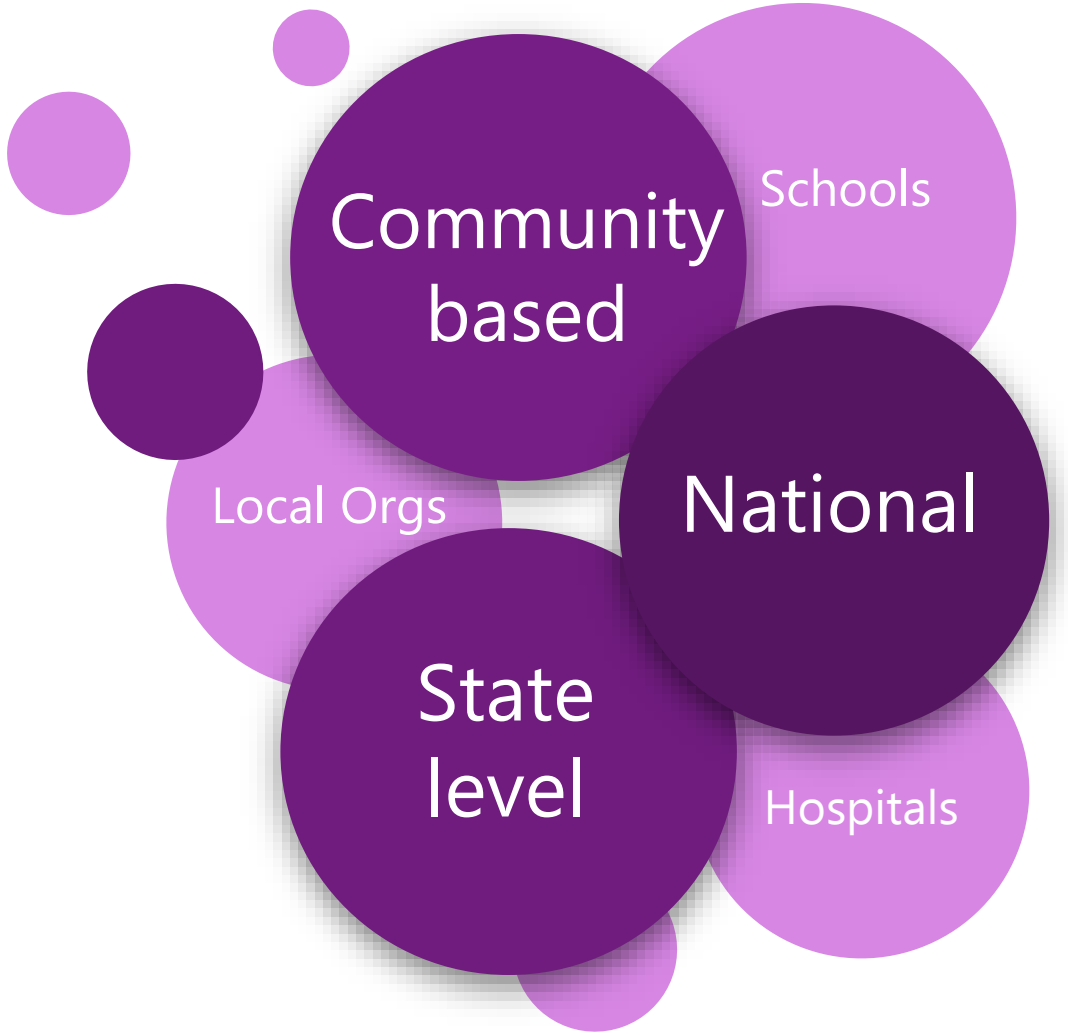
Radhakrishnan et al., 2022

Eating disorders and social inequities

- Disproportionately **high risk** and **barriers to accessing care** for LGBTQIA+, Black and Latine, and lower-income youth in the U.S.
- Associated with social media use, violence and bullying victimization, food insecurity, and other adverse childhood experiences (ACEs)
- Urgent need for **enhanced prevention and surveillance** efforts

Beccia et al., 2019; Frieiro Padín et al., 2023; Hazzard et al., 2020; Sonneville et al., 2018

Eating Disorder Prevention and Intervention Efforts



Organizations nationwide are dedicated to the work in countless ways.

National legislative efforts

Nutrition CARE Act (H.R. 6961/S. 3010)

- Proposed bill would fix a gap in Medicare Part B coverage, which excludes individuals with eating disorders from receiving medical nutrition therapy - an essential component of eating disorders treatment.

Kids Online Safety Act (H.R. 7891/S. 1409)

- Comprehensive social media platform accountability bill that seeks to address specific harms posed by platform algorithms, including those that contribute to disordered eating behaviors, eating disorders and suicidal ideation.

EDC EATING DISORDERS COALITION FOR RESEARCH, POLICY & ACTION

State-level efforts

WV

HB 4047 (2022): requires all school employees and school district volunteers in the state to complete training every three years on how to recognize, prevent and respond to students' self-harm behaviors and eating disorders.

CO

SB 23-14, 23-176 (2023): establishes a state-level disordered eating prevention program; requires creation of a public-facing resource database; limits the use of body mass index in determining treatment; bans the sale of diet pills to minors

PA

HB 27 (2023): requires schools to issue annual education to parents of kids in grades 6-12 about eating disorders and mandates creation of a state task force to develop guidance and educational resources.

KY

KRS 210.051 (2020): established the KY Eating Disorder Council. The Council is charged with, among other goals, working with the Cabinet for Health and Family services to examine surveillance systems for best strategies for implementation of services.

VT

Act 115 (2023): created Eating Disorder Working Group to assess services available and make recommendations to improve access. Led to creation of Eating Disorder Education Guidelines for School Employees (2023)

Without consistent surveillance of eating disorder-related trends, we limit our ability to measure the impact of initiatives at all levels.

Advancing the surveillance of eating disorders among youth

Youth Risk Behavior Survey

- Biennial population-based survey of U.S. middle and high school students that collects information on priority health topics:
  - Diet & physical activity, substance use, sexual behaviors, injuries & violence, and adverse childhood experiences (e.g., unstable housing)

- **Purpose**: Monitor adolescent health over time, identify emerging issues, and plan and evaluate programs to support youth health

- Standard, national, and **state-specific** questionnaires

How the YRBS can advance the prevention of eating disorders among U.S. youth

Monitor trends

Identify inequities

Document spikes

Inform interventions

Track progress

Eating disorder surveillance in the YRBS

1995–2013

- Standard Survey includes three relevant items:
  - Fasting, purging, and diet pill use

CDC's YRBS Disordered Eating Items, 1995–2013

Fasting Item

During the past 30 days, did you **go without eating for 24 hours or more** (also called fasting) to lose weight or to keep from gaining weight?

A. Yes
B. No

Purging Item

During the past 30 days, did you **vomit or take laxatives** to lose weight or to keep from gaining weight?

A. Yes
B. No

Diet Pill Use Item

During the past 30 days, did you **take any diet pills, powders, or liquids** without a doctor's advice to lose weight or to keep from gaining weight? (Do not include meal replacement products such as Slim Fast.)

A. Yes
B. No

Eating disorder surveillance in the YRBS

1995–2013

- Standard Survey includes three relevant items:
  - Fasting, purging, and diet pill use

2015

- All three items removed from the Standard Survey

STAT

HEALTH

A decade without data: Eating disorder researchers say a gap in CDC survey has left them flying blind

By Theresa Gaffney Dec. 9, 2021

Eating disorder surveillance in the YRBS

1995–2013

- Standard Survey includes three relevant items:
  - Fasting, purging, and diet pill use

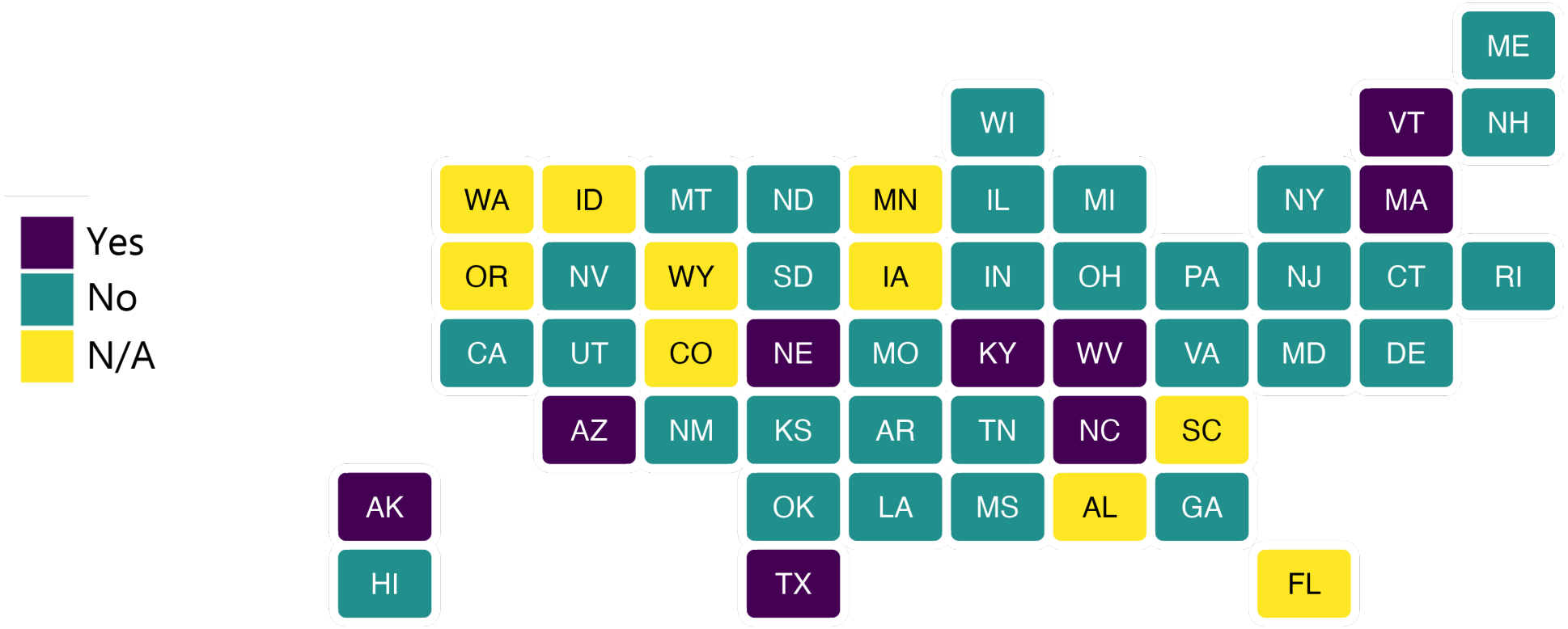
2015

- All three items removed from the Standard Survey

2015–23

- Item inclusion and selection at the discretion of states

States that included eating disorder items in their 2023 YRBS questionnaire



Eating disorder surveillance in the YRBS

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2015–23

- Item inclusion and selection at the discretion of states

2024

- Proposed items for inclusion on 2025 Standard Survey

Standardizing eating disorder assessment

Binge Eating: During the past 30 days, on how many days did you eat an unusually large amount of food in a short period of time and experience a loss of control over how much you were eating or a feeling that you could not stop eating even when full?

A. 0 days; B. 1 or 2 days; C. 3 to 5 days; D. 6 to 9 days; E. 10 to 19 days; F. 20 to 29 days; G. All 30 days

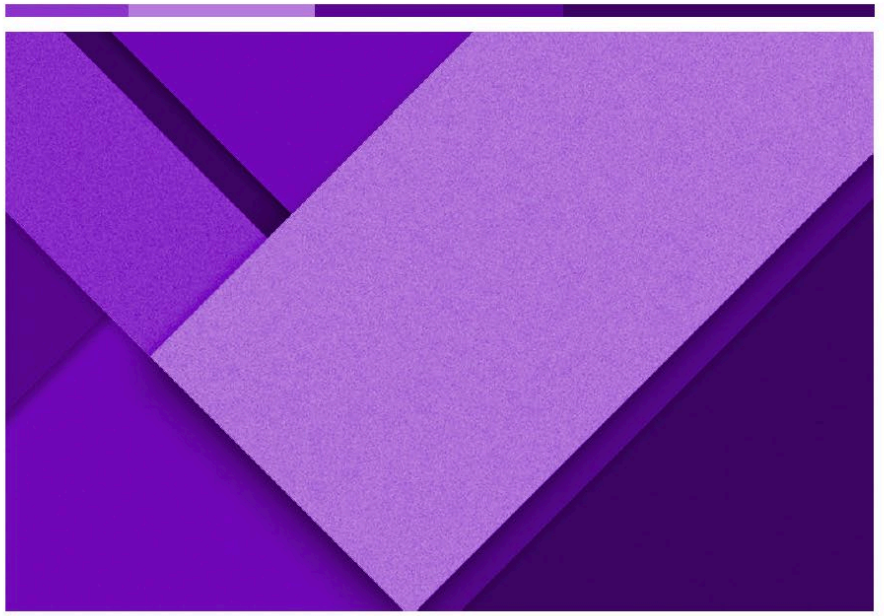
Composite Restrictive Disordered Eating: During the past 30 days, on how many days did you try to control your shape or weight by fasting or skipping meals; taking diet pills or supplements not prescribed by a doctor; or vomiting or taking laxatives?

A. 0 days; B. 1 or 2 days; C. 3 to 5 days; D. 6 to 9 days; E. 10 to 19 days; F. 20 to 29 days; G. All 30 days

Resource #1:

Literature review and full detailed report

Scan to download!



Assessing Disordered Eating in the Youth Risk Behavior Survey (YRBS)

Best Practices and Recommendations for Item Selection

—

Developed by the Eating Disorder Public Health Surveillance Working Group, with support from The Trevor Project, Harvard STRIPED, the Academy for Eating Disorders (AED)'s Epidemiology & Public Health Committee, and the Kentucky Eating Disorder Council

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Resource #2:

Reference guide for YRBS coordinators

Scan to download!

Assessing Disordered Eating in the Youth Risk Behavior Survey (YRBS)

Best Practices and Recommendations for Item Selection

The public health burden of disordered eating. Eating disorders are serious mental illnesses that are characterized by significant disturbances to one's eating patterns and/or body image and they represent a growing public health threat for U.S. youth [1]. These disorders, which include anorexia nervosa, bulimia nervosa, and binge eating disorder, affect 7% of adolescents [2,3] and are associated with **long-lasting adverse medical consequences** spanning from cardiovascular complications, bone loss, and endocrine abnormalities to depression, anxiety, suicidality, and substance use [4,5]. They are also known to result in considerable psychosocial disability, reduced quality of life, and substantially elevated mortality [2,6]. Even when diagnostic criteria are not met, subthreshold symptoms and behaviors (e.g., binge eating, purging) can cause similar levels of impairment [7] and are **highly prevalent**, affecting **10% of boys and 23% of girls** aged 14–18 [8]. Concerningly, these numbers have only increased since 2020 as a result of the COVID-19 pandemic and ongoing youth mental health crisis [9,10], as well as the prevailing influence of weight stigma [11]. At the population-level, the full spectrum of disordered eating **costs the U.S. economy $65 billion per year** in productivity losses and healthcare expenditures [12,13], underscoring the substantial burden that these outcomes put on individuals, families, and society.

Urgent need for surveillance. Comprehensive, up-to-date surveillance data on disordered eating are urgently needed to **inform treatment and prevention efforts**. To help achieve this goal, this resource has been developed by a multi-state Eating Disorder Public Health Surveillance Working Group and contains evidence-based, **best practice recommendations** for the selection and prioritization of disordered eating questions in state-specific YRBS surveys. Its aims are to support YRBS Coordinators who are deciding to prioritize the assessment of disordered eating in their survey, while simultaneously navigating decisions about which symptoms and behaviors to assess within the often limited number of available question slots.

References

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Eating Disorder Public Health Surveillance Working Group

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Eating Disorders Public Health Surveillance Working Group

The Eating Disorders Public Health Surveillance Working Group is a multi-state, interdisciplinary group of researchers and professionals united by a shared goal of advancing the surveillance of eating disorders in the U.S., with a particular focus on surveillance through the Centers for Disease Control and Prevention (CDC)'s Youth Risk Behavior Survey (YRBS). Members include state YRBS coordinators, epidemiologists, and public health and medical professionals. Established in 2022, our goal is to ensure the routine collection of eating disorder data among youth in the U.S. so as to help inform treatment, prevention, and health equity interventions. This has included efforts to improve the surveillance of disordered eating behaviors in the YRBS at both the federal and state level, with important wins thus far in Alaska and Arizona.

If you have a question for the Working Group or are interested in joining, please fill out this form!

Value of collecting disordered eating data

Validate disordered eating prevalence as a public health concern & inform interventions

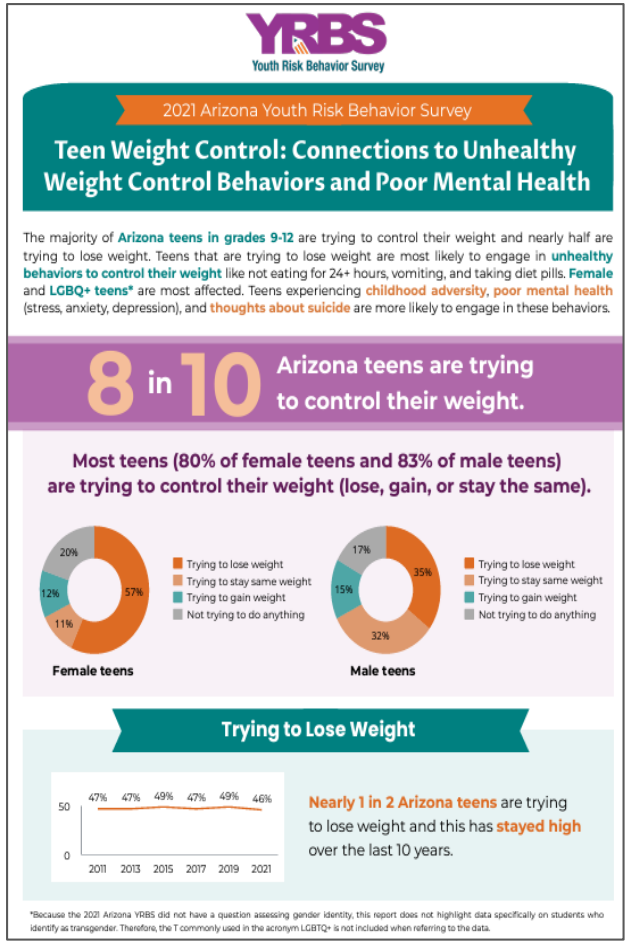
- Snapshot of teen behavior (spikes, inequities)
- Track trends in your state over time
- Comparison to national and other states' prevalence *(importance of clear best practice recommendations for question selection)*

Disseminate data to communities and professionals

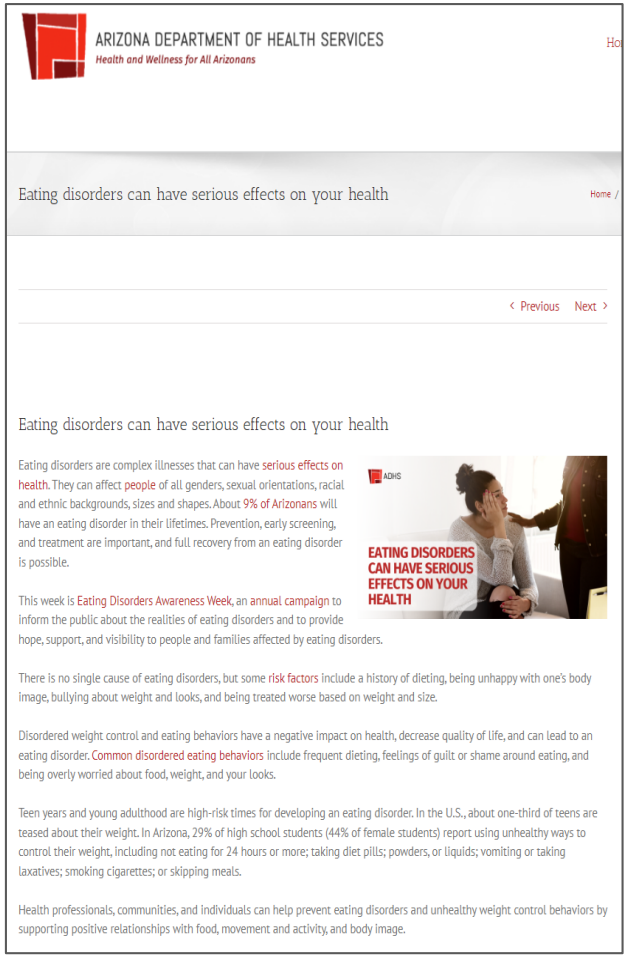
- Training and conferences
- Data graphics
- Media and blogs, social media
- Youth health and mental health reports
- Published manuscripts
- Policy briefs

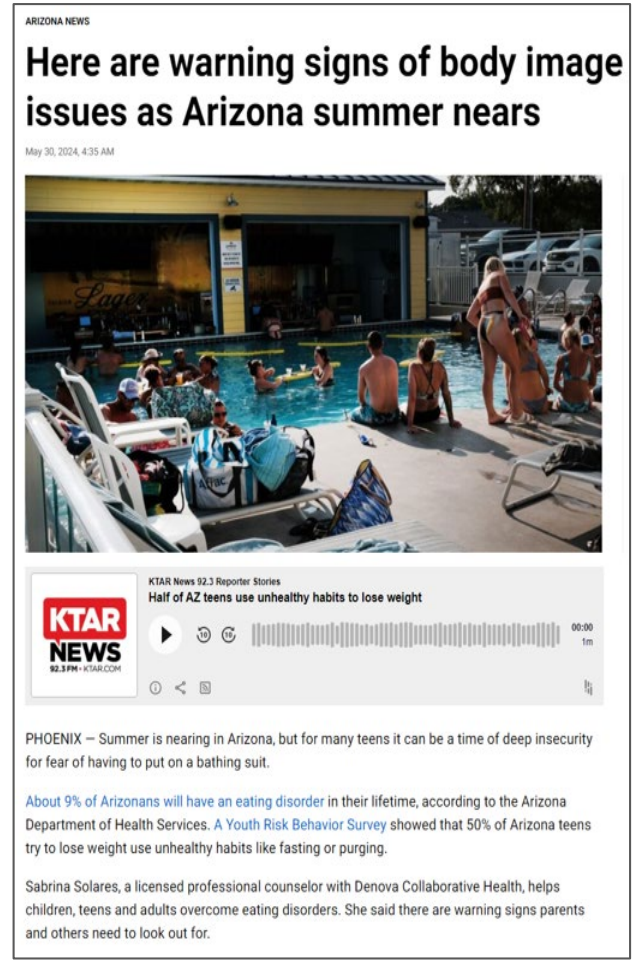
Use & **Disseminination** of Disordered Eating Data

Data Graphics



Media & Blogs





Use & **Dissemination** of Disordered Eating Data

Reports

Youth-reported:

Unhealthy Weight Control Behaviors

The 2017 and 2021 Youth Risk Behaviors Surveys (YRBS) assessed unhealthy weight control behaviors by asking "*During the past 30 days, did you try to lose weight or keep from gaining weight by going without eating for 24 hours or more; taking any diet pills, powders, or liquids; vomiting or taking laxatives; smoking cigarettes; or skipping meals?*" Please note that the unhealthy weight control behavior question in the 2017 YRBS did not include cigarette smoking, and the question does not contain all disordered eating behaviors, but it does provide valuable insight into the prevalence of some behaviors and the data shows this is a growing public health concern among Arizona adolescents.

Unhealthy weight control and disordered eating behaviors have a negative impact on physical and mental health, decrease quality of life, and can lead to an eating disorder.

Figure 4 Unhealthy Weight Control Behaviors

Between 2017 and 2021 YRBS, unhealthy weight control behaviors have increased by about 48% (from 20% to 29%). This is a significant increase, even after accounting for changes in the questionnaire about the behaviors.

1 in 2 adolescents who are trying to lose weight are engaging in unhealthy weight control behaviors and 1 in 3 adolescents who are trying to stay the same weight are engaging in unhealthy weight control behaviors. This shows that **when adolescents try to control their weight, they often use unhealthy behaviors**.

It is also important to note that adolescents experiencing poor mental health and reporting suicide considerations also have higher rates of unhealthy weight control behaviors.

11

Research Manuscripts

ELSEVIER

Eating Behaviors
Volume 34, August 2019, 101299

Risk of disordered eating at the intersection of gender and racial/ethnic identity among U.S. high school students

Ariel L. Beccia [a b], Jonggyu Baek [b], William M. Jesdale [b], S. Bryn Austin [c d], Sarah Forrester [b], Carol Curtin [e], Kate L. Lapane [b]

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Highlights

- Disordered eating (DE), particularly fasting, is prevalent among adolescents.
- Girls of all racial/ethnic identities are more likely than White boys to report DE.
- Racial/ethnic minority boys are more likely than White boys to report DE.
- Hispanic/Latina girls have excess risk related to multiply marginalized identity.

Abstract

Policy Briefs

POLICY BRIEF STRIPED — Strategic Training Initiative for the Prevention of Eating Disorders

What Do Dietary Supplements Have to Do With Eating Disorders Prevention?

WHAT IS THE PROBLEM?

Eating disorders are a serious public health problem affecting youth and adults of all races, ages, and genders. In recent years, research has illuminated significant health disparities in eating disorders: girls report more eating disorder symptoms than do boys[1]; sexual minority and transgender youth are likelier to develop eating disorders than their heterosexual and cisgender counterparts[2–4]; youth of color are equally likely as white youth to develop eating disorders but less likely to access treatment.[5,6] Eating disorders are associated with a number of serious health risks including osteoporosis and heart disease.

Eating disorders are diagnosed based on a number of criteria, including the presence of what clinicians call unhealthy weight control behaviors (UWCBs). These behaviors can constitute either a symptom or a risk factor for eating disorders, depending on a person's other behaviors. One UWCB of particular concern is the use of pills or powders to lose weight or build muscle, which are often sold as dietary supplements. *Although they are sold alongside multivitamins and other supplements largely regarded as safe, these products often contain unlisted, illegal pharmaceutical ingredients that pose serious risks.*[12]

Under the Dietary Supplement Health and Education Act of 1994 (DSHEA), the U.S. Food and Drug Administration (FDA) does not have the authority to require proof of safety or efficacy prior to the sale of these products.[7] While some voluntary certifications exist, there is no guarantee that a supplement contains what the label says it does. *Supplements sold for weight loss and muscle-building have been found to contain substances including untested designer amphetamine analogues, psychotropic drugs, and the active ingredient from the failed weight-loss drug Meridia, which was pulled from the market in 2010.* These products have been linked to outbreaks of liver injury,[8] some severe enough to require transplantation,[9] and have even caused several high-profile deaths in recent years.[10,11]

While DSHEA does grant the FDA the power to test products on the market and initiate recalls, this is not an effective means of protecting the public: One recent study found that two-thirds of recalled supplements still contained contaminants six months after the recalls were initiated.[12] Despite the harms these products can cause, the perception of risk associated with them is still low, and the U.S. market is estimated to exceed $40 billion.[13] *Given the severity and scope of this problem, policy intervention is warranted at the state and local level.*

WHAT CAN WE DO?

States and municipalities have a number of policy tools at their disposal that can reduce the threats these products pose. *Taxation* and *age restrictions* are two evidence-based public health policy strategies that have been used in a number of contexts to reduce youth access to dangerous products, most notably cigarettes and alcohol.

1

Take action in your state!

State YRBS Coordinators

1. Review the "Best Practice and Recommendations for Item Selection" resource & prioritize disordered eating items however possible
1. **Include recommended disordered eating items on your state's 2025 YRBS questionnaire**

Supportive resources

Assessing Disordered Eating in the Youth Risk Behavior Survey (YRBS)
Best Practices and Recommendations for Item Selection

STRATEGIC TRAINING INITIATIVE FOR THE PREVENTION OF EATING DISORDERS
STRIPED *ADVOCACY* PLAYBOOK

Take action in your state!

Researchers, public health professionals, advocates, etc.

1. Figure out who your state's YRBS coordinator is!

1. **Urge for the inclusion of recommended disordered eating items on your state's 2025 YRBS questionnaire (e.g., over email or in a meeting)**

Supportive resources

Assessing Disordered Eating in the Youth Risk Behavior Survey (YRBS)
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Recommendations for Item Selection

1 question slot available:

Binge Eating: During the past 30 days, on how many days did you eat an unusually large amount of food in a short period of time and experience a loss of control over how much you were eating or a feeling that you could not stop eating even when full? A. 0 days; B. 1 or 2 days; C. 3 to 5 days; D. 6 to 9 days; E. 10 to 19 days; F. 20 to 29 days; G. All 30 days.

Rationale: This question will estimate the prevalence of binge eating, which is the most common form of disordered eating among U.S. youth. Binge eating is a core symptom of bulimia nervosa (BN) and binge eating disorder (BED) is a high-risk disordered eating behavior in its own right that disproportionately affects racial/ethnic minority youth, LGBTQ+ youth, and youth experiencing food insecurity.

2 question slots available:

Add **Composite Restrictive Disordered Eating:** During the past 30 days, on how many days did you try to control your shape or weight by fasting or skipping meals; taking diet pills or supplements not prescribed by a doctor; or vomiting or taking laxatives? A. 0 days; B. 1 or 2 days; C. 3 to 5 days; D. 6 to 9 days; E. 10 to 19 days; F. 20 to 29 days; G. All 30 days.

Rationale: This question will estimate the prevalence of restrictive-type disordered eating behaviors. These behaviors often co-occur and can cause severe and sometimes long-lasting negative health consequences, including cardiovascular complications, bone loss, endocrine abnormalities, and neurological issues. They are also strongly associated with anxiety, depression, suicidality, and substance use and are among the strongest predictors of a future eating disorder diagnosis (especially anorexia nervosa) among youth in the U.S.

3 question slots available:

Add **Weight Victimization:** During the past 12 months, have you ever been the victim of teasing or name calling because of your weight, size, or physical appearance? A. Yes; B. No.

Rationale: This question will estimate the prevalence of victimization based on weight or shape, which is a robust predictor of disordered eating among youth. Importantly, girls, racial/ethnic minority youth, LGBTQ+ youth, and youth of higher weight status are most likely to be the targets of weight- or shape-related teasing or name calling, making this factor a recognized social determinant of disparities in disordered eating outcomes.

4 question slots available:

Add **Purging, Diet Pill Use, OR Fasting:** During the past 30 days, did you **vomit or take laxatives** to lose weight or to keep from gaining weight? A. Yes; B. No. During the past 30 days, did you **take any diet pills, powders, or liquids** without a doctor's advice to lose weight or to keep from gaining weight? (Do not count meal replacement products such as Slim Fast.) A. Yes; B. No. During the past 30 days, did you **go without eating for 24 hours or more** (also called fasting) to lose weight or to keep from gaining weight? A. Yes; B. No.

Rationale: These questions will provide more granular data on the prevalence of a specific restrictive-type disordered eating behavior, which may be relevant in some contexts.

CONNECT

with the working group

Eating Disorder Public Health
Surveillance Working Group

Thank you!

Please put any questions into the Q&A box.

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