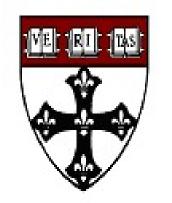
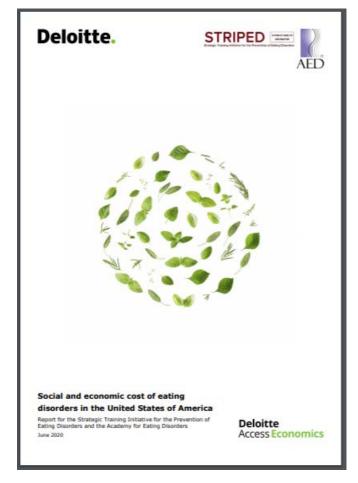
Social & Economic Cost of Eating Disorders in the United States

A Case Example of Strategic Science to Advance Policy Action for Eating Disorders



http://www.hsph.harvard.edu/striped







I have no financial disclosures or conflicts of interest.

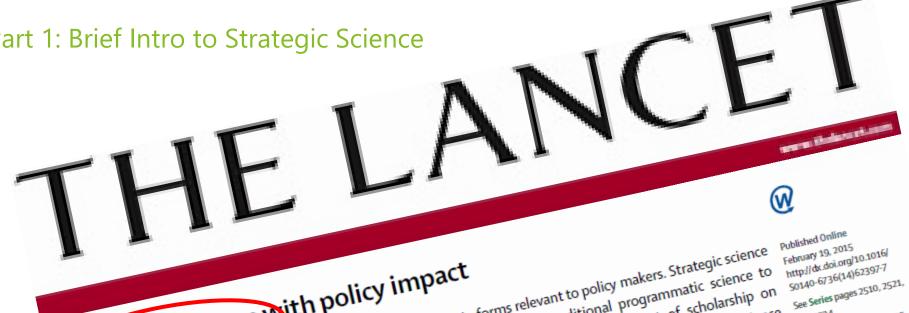
Overview of Presentation

- 1) Very brief introduction to strategic science
- 2) Key findings from social & economic impact report on eating disorders in U.S.
- 3) Bigger picture on report as case example of

strategic science

- Rationale
- Approach
- Amplification, policy translation
- 4) Concluding thoughts





Strategic science with policy impact

Evidence-based policy making is an important aspirational goal, but only a small proportion of research has the policy impact it might have. Most researchers are not trained to create policy impact from their work, ant with policy makers is not encouraged or and the communication the academic

also in forms relevant to policy makers. Strategic science can complement traditional programmatic science to better realise the potential impact of scholarship on policy. We have developed a model of strategic science and 2534 See Comment Lancet 2015; (figure), which we have applied to our work on nutrition 385: 2326 policy, obesity prevention, and food systems research, and food systems research, See Series Lancet 2015; 385: 2400, 2410, and 2422 but have designed the model to be broadly applicable

ton in our model is to identify agents for other fields of research. cinrocal information flow Investigators

Brownell & Roberto, *The Lancet* 2015 but little is done

When the broad gap between evidence and Po addressed in academic settings, the proposed solution is generally to disseminate research findings to the to policy. media and perhaps policy makers. This approach is helpful, but overlooks the importance of information flow from the policy world into research settings. The creation of a two-way policy bridge between researchers and policy makers can help to ensure that research addresses issues relevant to policy and that research findings are communicated in real time to often must make decisions quickly. tighter interaction

from individuals or institutions III a r policy advances. Such input can uncover impurbut it can also be no gaps in knowledge that have not been identified in



"Research designed to address gaps in knowledge important to policy decisions, derived from the reciprocal flow of information between researchers and policymakers..."

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and clinicians, <-experts by experience

"...and communicated not only in scholarly publications but also in forms relevant to policymakers."

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Deloitte.





Social and economic cost of eating disorders in the US

Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders

June 2020



Key takeaways of report

Eating disorders are:

Common

Deadly

Expensive

Deloitte.





Social and economic cost of eating disorders in the United States of America

Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders

Deloitte Access Economics

Nearly 30 million Americans alive today – or 9% of the population – will have an eating disorder at some point during their lives, either in the past, present or future.

Nearly 2 million children alive today will have an eating disorder before they are 20 years old.

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





PREVALENCE & MORTALITY



Percent of the U.S. population, or 28.8 million Americans, that will have an eating disorder in their lifetime

10,200 deaths per year as a direct result of an eating disorder, equating to 1 death every 52 minutes



EATING DISORDERS AFFECT EVERYONE:



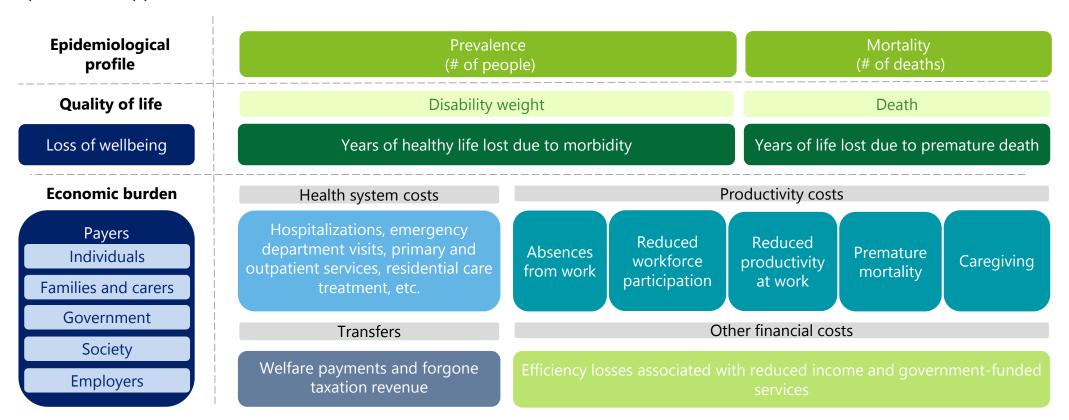
- All ages, starting as young as 5 years old to over 80 years old
- All races, however, people of color with eating disorders are half as likely to be diagnosed or to receive treatment
- All genders, with females being 2x more likely to have an eating disorder
- All sexual orientations

Study using cost-of-illness modeling

A standard methodology used to estimate financial costs & reduction in wellbeing due to a condition

Costs of eating disorders include financial costs to the health system, productivity losses, informal caregiving, and other financial costs. The costs of eating disorders also include the reduction in wellbeing for people living with eating disorders.

Costs were estimated from a societal perspective for the fiscal year 1 October 2018 – 30 September 2019 using a prevalence approach.



COST TO ECONOMY & SOCIETY

Yearly economic cost of eating disorders

Additional loss of wellbeing per year

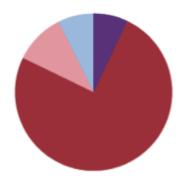
Cost Breakdown:

Productivity Losses (\$48.6B)

Informal Care (\$6.7B)

Efficiency Losses (\$4.8B)

Health System (\$4.6B)



COST TO HOSPITAL SYSTEMS:

53,918 **ER visits**



costing \$29.3M **23,560** inpatient hospitalizations



costing \$209.7M

LOSS PER GROUP:







\$16.3B **Employers**



¹Sonneville KR, Lipson SK. Disparities in eating disorder diagnosis and treatment according to weight status, race/ethnicity, socioeconomic background, and sex among college students. International Journal of Eating Disorders 2018: 1-9.





















NCEED

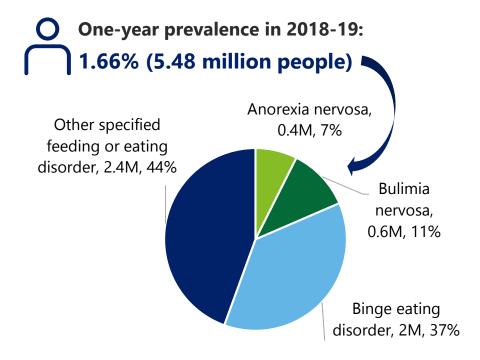




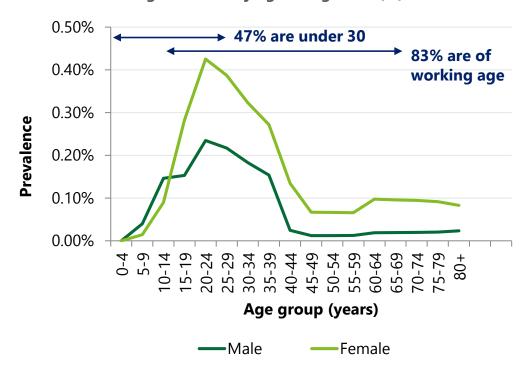


Prevalence

5.48 million Americans had an eating disorder (ED) during 2018-19



Prevalence of eating disorders by age and gender (%), 2018-19



Deaths associated with eating disorders in 2018-19: Approx. 10,200 (range of 5,500-22,000)

Lifetime prevalence as of 2018-19:

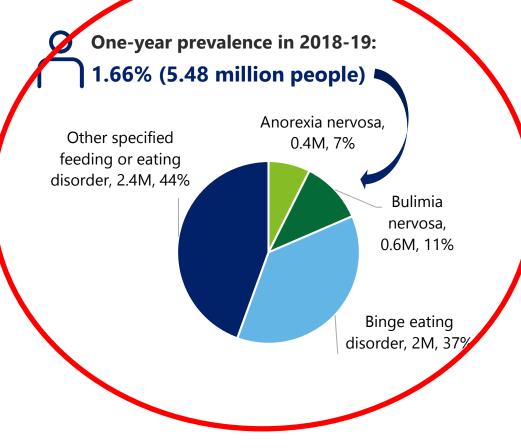
8.6% for females (14.4 million cases)

4.1% for males (6.6 million cases)

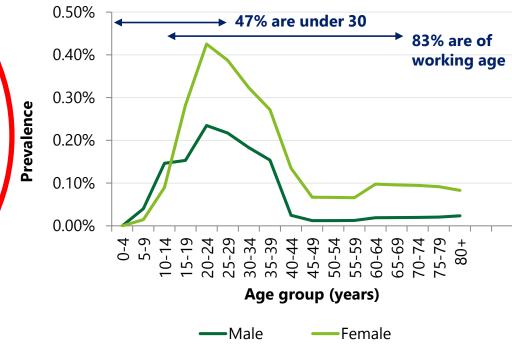


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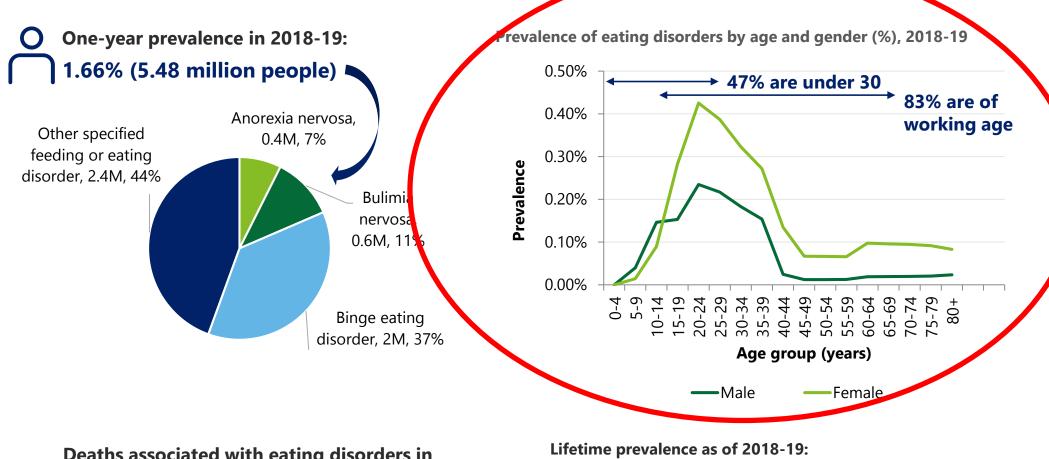
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Financial costs

The total financial costs of eating disorders are large, and there is a substantial reduction in wellbeing

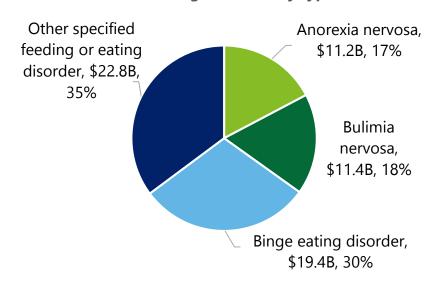
The annual financial cost of eating disorders was \$64.7 billion in 2018-19, which equated to \$11,808 per person with an eating disorder.

The average annual cost per person was greatest for anorexia nervosa (\$27,400), followed by bulimia nervosa (18,300).

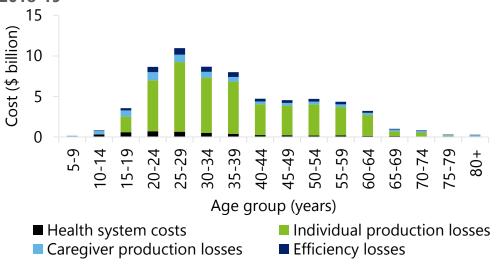
Financial costs of eating disorders by cost component, 2018-19

Cost component	Total cost (\$M)	Per person with condition (\$)	Proportion (%)
Health system	4,555.4	831	7.0%
Productivity losses	48,634.3	8,874	75.2%
Informal care	6,731.4	1,228	10.4%
Efficiency losses	4,794.8	875	7.4%
Total financial costs	64,716.0	11,808	100.0%

Financial costs of eating disorders by type, 2018-19



Financial costs of eating disorders by cost component and age, 2018-19



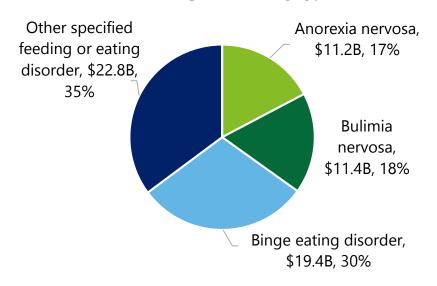
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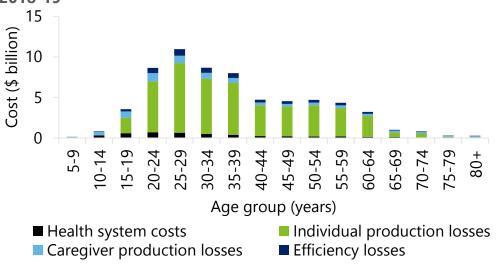
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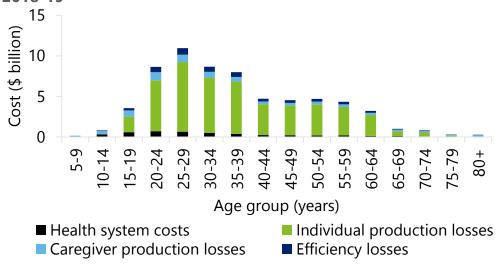
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Financial costs of eating disorders by type, 2018-19 Other specified Anorexia nervosa. feeding or eating \$11.2B, 17% disorder, \$22.8B, 35% Bulimia nervosa, \$11.4B, 18% Binge eating disorder, \$19.4B, 30% © 2020 Deloitte Touche

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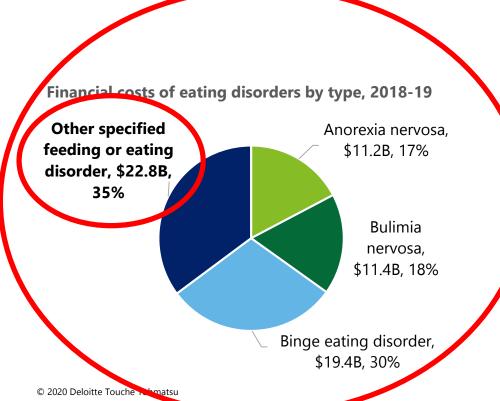
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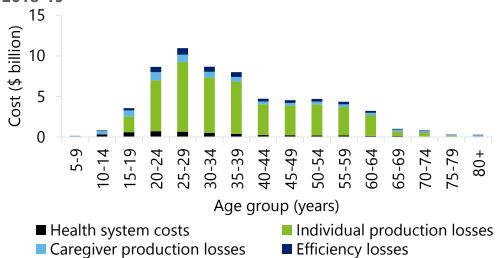
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21

The vast majority of health system costs of eating disorders was due to primary and outpatient care

Health system costs due to eating disorders totaled \$4.6 billion, or \$831 per person with an eating disorder.

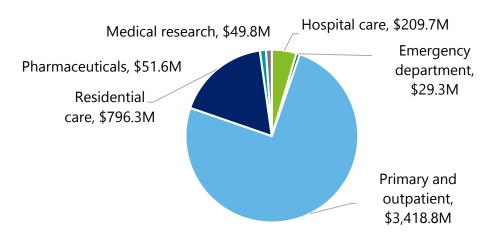
The estimated average cost per person was highest for individuals with anorexia nervosa (\$2,615), followed by those with bulimia nervosa (\$1,335).

Further research is required to better understand the costs of medical nutrition therapy. These costs may also be substantial (up to \$570 million).

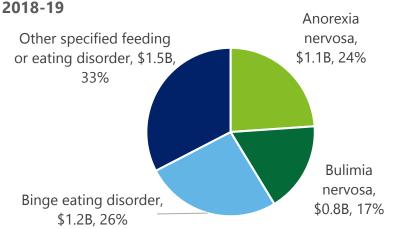
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"Intensive outpatient care was a significant financial burden. Asking staff how people could afford this care they said often second mortgages were taken, dipping into college savings plans."

Health system costs of eating disorders by cost type, 2018-19



Health system costs of eating disorders by eating disorder,



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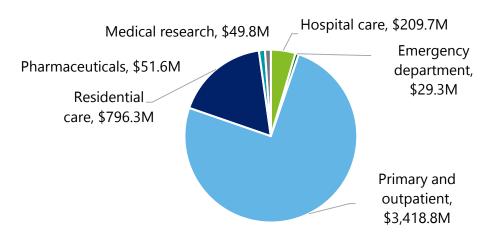
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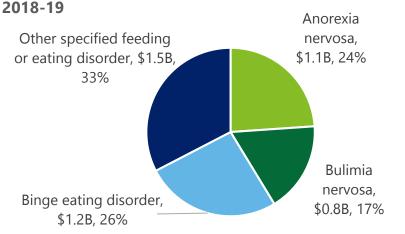
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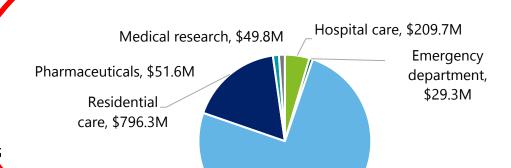
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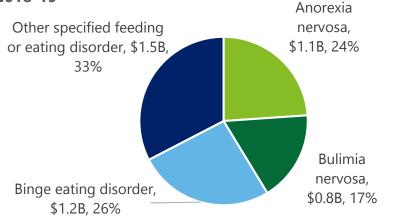


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Primary and

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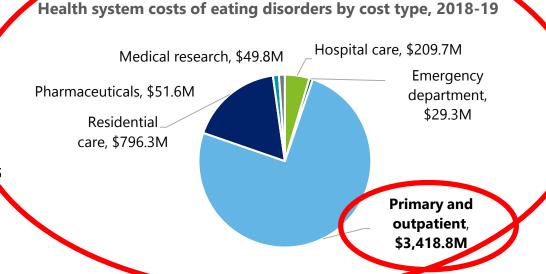
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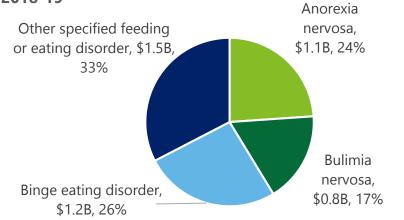
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Productivity costs

Productivity costs of eating disorders largely made up of presenteeism & reduced employment, with costs being borne by individuals, employers & government

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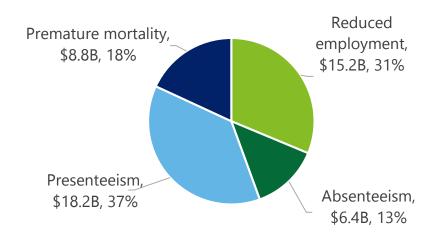
Individuals with anorexia nervosa or bulimia nervosa were estimated to be absent from work for an additional 27.3 days per year, which was lower for other eating disorders (4.2 days per year).

Presenteeism impacts were also substantial (~10% lower work output).

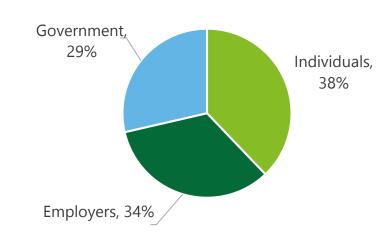
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Productivity costs of eating disorders by type, 2018-19



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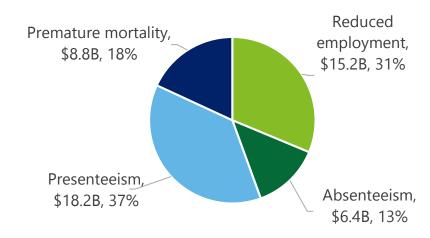
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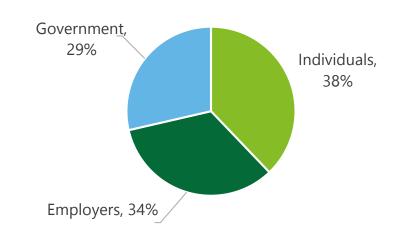
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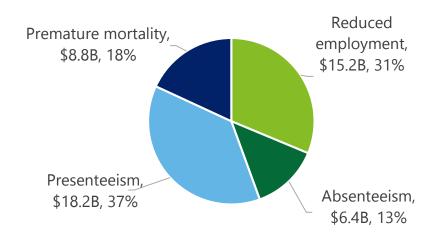
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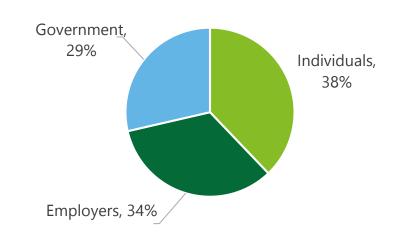
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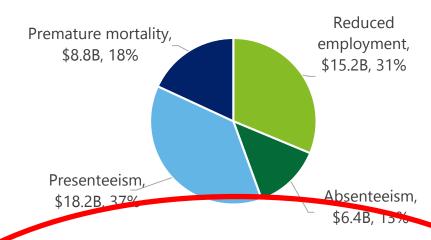
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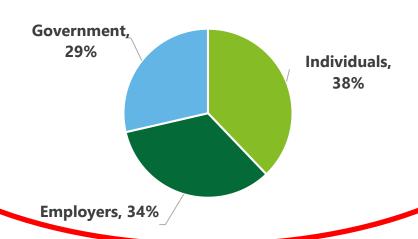
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Other financial costs

Other financial costs of eating disorders were made up of informal care costs and efficiency losses, at \$11.5B combined

Informal care costs

Informal caregiving for eating disorders was estimated to cost \$6.7 billion in 2018-19.

Efficiency losses

Efficiency losses due to eating disorders were estimated to cost \$4.8 billion in 2018-19.

Informal care cost an average of \$1,228 per person with an eating disorder.



Approximately 23.6% sought help from a loved one or close friend, meaning there were 1.3m caregivers.



Each caregiver provided 4.45 hours of care per week on average, or 5.8 full-time working weeks per annum.



5.8m hours of informal care were provided in 2018-19, which equates to **144,000 full-time** working weeks.

"The emotional toll of the condition was significant. Our family was separated for one year across continents. As a family of five, we each blamed ourselves, thinking that we were the problem that may have resulted in our daughter nearly losing her life."

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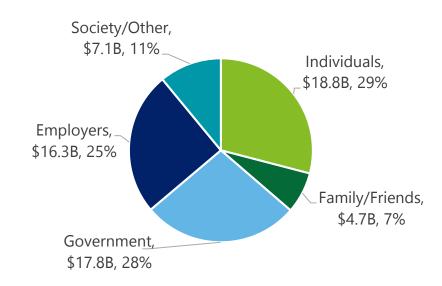
Who bears the cost?

Individuals bear the largest share of the financial costs of eating disorders in the U.S. in 2018-19, followed by government and employers

The total financial costs borne by people living with eating disorders and their loved ones was \$23.5 billion in 2018-19, which includes out-of-pocket payments for health care (\$363.5 million).

Government taxation revenue was reduced by \$16.0 billion, and governments also paid \$1.8 billion to fund health and other services in 2018-19.

Financial costs of eating disorders by payer, 2018-19

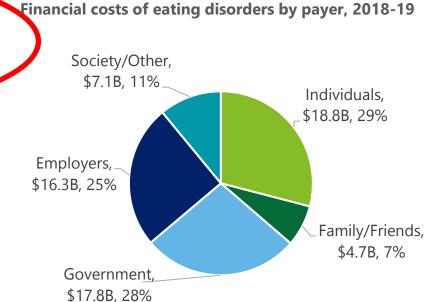


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Wellbeing costs

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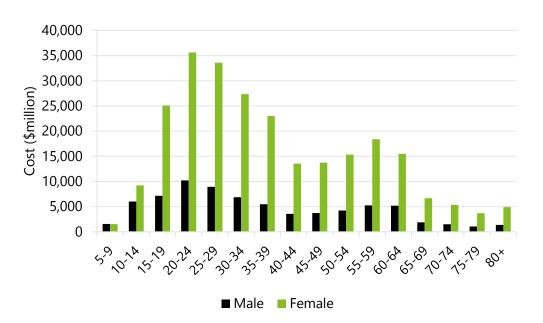
1.3 million DALYs were lost due to eating disorders in 2018-19, which represented approximately 1.2% of the total burden of disease in the US.

The loss of wellbeing value was estimated to be \$326.5 billion in 2018-19, at an average cost of \$59,600 per person with an eating disorder.

"The emotional toll was significant. I often felt belittled when I dealt with clinicians who were not competent in the treatment of my

condition."

Loss of wellbeing due to eating disorders by age and gender, 2018 -19



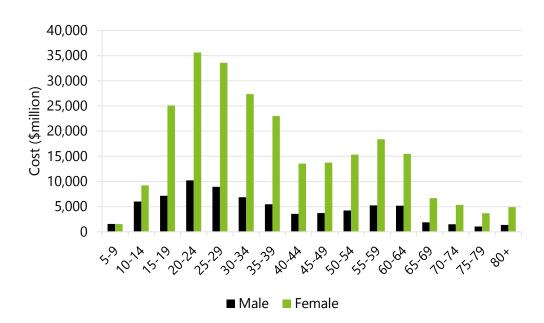
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"The emotional toll was significant. I often felt belittled when I dealt with clinicians who were not competent in the treatment of my condition." Loss of wellbeing due to eating disorders by age and gender, 2018 -19



Part 2: Key Findings

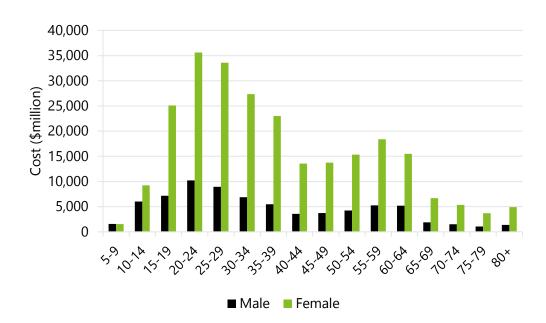
Wellbeing costs

Wellbeing costs of eating disorders in 2018-19 were significant, with the 15-39 age group bearing the highest wellbeing costs

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Cost to economy comparable to or exceeds other serious conditions in U.S.

- Parkinson's disease: \$53.8 billion in 2019 USD
- Schizophrenia: range from \$27.6 billion to \$111 billion in 2019 USD

Implications

 Understanding social & economic costs essential to inform resource allocation for research, treatment, prevention

- Most comprehensive study to date
 - Demonstrates depth & breadth of impact of eating disorders

Future areas of research

Looking ahead

More research needed into cost-effective treatment & prevention options to reduce cost of eating disorders to U.S. society



Further research required to understand and estimate the additional costs of eating disorders that may be attributable to structural racism and other structural oppressions in the U.S.



More research needed to estimate cost-effectiveness of stepped, integrated care models to reduce burden of eating disorders.



Future research required to understand long-term impacts of eating disorders and impact of comorbidities on costs associated with eating disorders.



Further research needs to be undertaken to estimate costs that may be prevented through early intervention and prevention of eating disorders.

The bigger picture

Deloitte.





Social and economic cost of eating disorders in the United States of America

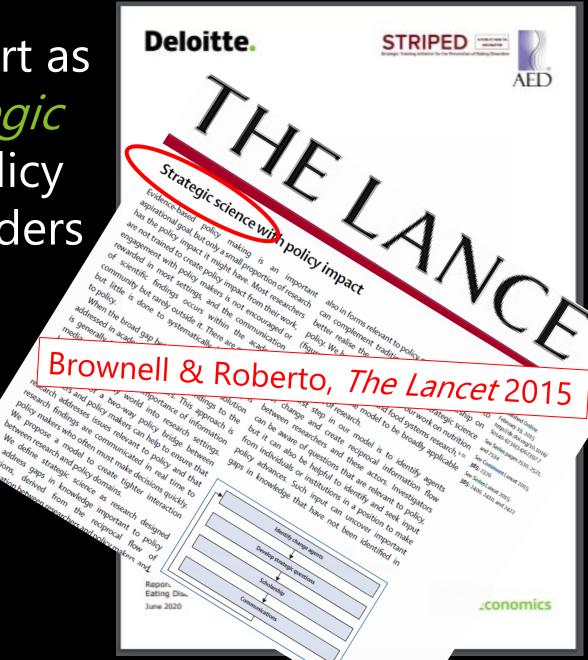
Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders June 2020

Deloitte Access Economics

The bigger picture

Economic impact report as case example of strategic science to advance policy action for eating disorders

- Rationale
- Approach
- Amplification, policy translation



Part 3: Bigger Picture

Rationale

 Several years ago, three major national eating disorders cost-of-illness reports released globally:

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 - 2012 & 2015: Australia's Butterfly Foundation contracted with Deloitte Access Economics



 Several years ago three major national eating disorders cost-of-illness reports released globally:

 2012 & 2015: Australia's Butterfly Foundation contracted with Deloitte Access Economics

2015: U.K.'s Beat contracted with PWC







Inspired by Butterfly's achievements in leveraging their
 Australian reports & subsequent strategically targeted survey

• Goal: We sought to follow Butterfly's & Beat's lead in the U.S.



 Inspired by Butterfly's achievements in leveraging their Australian reports & subsequent strategically targeted survey



By Kate Aubusson May 3, 2018 - 7.30pm paid for his weekly sessions with a psychologist.

Goal: We sought to follow Butterfly's & Beat's lead in the U.S.



Inspired by Butterfly's achievements in leveraging their
 Australian reports & subsequent strategically targeted survey



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Approach

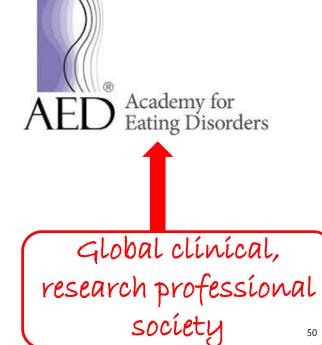
- We contacted Deloitte team that had done Australian report to determine interest, capacity
- Partnership of STRIPED & Academy for Eating Disorders, funded by STRIPED to contract with Deloitte

Goal: To ensure close collaboration across sectors to enhance visibility & credibility

Academic







Approach

- Assembled advisory panel with diverse expertise
 - Goal: Ensure range of technical & stakeholder perspectives at table
 - Panel Members' Sectors
 - Academía Busíness
 - community · Government
 - adjacent



Tracy Richmond



Johanna Kandel



Bryn Austin



Davene Wright



Katrina Velasquez



Rebecca Hutcheson



Mihail Samnaliev



Ruth Weissman



Jillian Lampert



Zachary Ward



Elissa Myers

Approach

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 - Goal: Ensure range of technical & stakeholder perspectives at table

Panel Members' Sectors

- Academía
 - Business
- Community Government
 - adjacent

Panel Members' Expertise Health Decision

- economics sciences
- Medicine

- Psychology
- Policymaking Experts by Epidemiology experience



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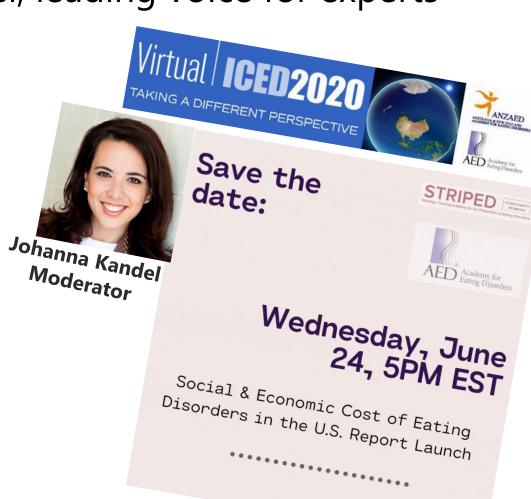
Part 3: Bigger Picture

Amplification With Unified Voice

 Report release & press conference timed with Virtual ICED 2020 with Deloitte team & myself

Moderated by Johanna Kandel, leading voice for experts-

by-experience



 Report release & press conference timed with Virtual ICED 2020 with Deloitte team & myself

Moderated by Johanna Kandel, leading voice for experts-

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 Facebook Live interviews with community advocates







 Report release & press conference timed with Virtual ICED 2020 with Deloitte team & myself

Moderated by Johanna Kandel, leading voice for experts-

by-experience

 Facebook Live interviews with community advocates





 Goal: To communicate with community advocates on key findings, call for policy action in context of lived experience



 Coordinated a dozen major eating disorders organizations in U.S. to amplify in unison with shared infographic & social media

























Coordinated a dozen major eating disorders organizations in
 U.S. to amplify in unison with shared infographic & social media

Goals:

- To speak with one, unified voice from community on the key findings, call for policy action
- To ensure report findings integrated consistently in communications
 & meetings led by other major ED federal advocacy groups























1-page infographic with all partnering organizations' logos

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



LINK TO REPORT



PREVALENCE & MORTALIT



Percent of the U.S. population, or 28.8 million Americans, that will have an eating disorder in their lifetime



EATING DISORDERS AFFECT EVERYONE:



- All ages, starting as young as 5 years old to over 80 years old
- All races, however, people of color with eating disorders are half as likely to be diagnosed or to receive treatment
- All genders, with females being 2x more likely to have an eating
- · All sexual orientations

COST TO ECONOMY & SOCIETY

\$64.7 **1** Yearly economic cost of eating disorders

of wellbeing per year

COST TO HOSPITAL SYSTEMS:

53,918 **ER visits**



costing \$29.3M 23,560 inpatient hospitalizations



costing \$209.7M Productivity Losses (\$48.6B) Informal Care (\$6.7B)

Efficiency Losses (\$4.8B)

Health System (\$4.6B)



LOSS PER GROUP:







\$16.3B























- 1-page infographic with all partnering organizations' logos
- Social media assets with weeklong schedule for release



SOCIAL & ECONOMIC COST OF EATING DISORDERS IN THE UNITED STATES

Did you know, there are 10,200 deaths eating disorder? Report by the Strategic Training Initiative for the Prevention of Eating Disorders Academy for Eating Disorders, and Deloitte Access Economics





- All ages, starting as young as 5 years old to over 80 years old
- All races, however, people of color with eating disorders are half as likely to be diagnosed or to receive treatment
- All genders, with females being 2x more likely to have an eating

LOSS PER GROUP:

Cost Breakdown:

\$23.5B

roductivity Losses (\$48.6B)



Eating disorders affect all genders, but females are 2x vide 6 weeks of haid care per year more likely than males to

have an eating disorder. Social & Economic Cost of Eating

Disorders in the U.S. Report \$16.3B #EDawareness













Families and individuals provide 6 weeks worth o informal, unpaid car per yea

STRIPED AMAGENTA

Social & Economic Cost of Eating Disorders in the U.S. Report #EatingDisordersCosts













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Translation to Policymakers

Contracted with Capitol Hill-based government relations
 & communications firms





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Translation to Policymakers

Contracted with Capitol Hill-based government relations
 & communications firms





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Eating disorders cost US \$65 billion a year: Here's what agencies can do

BY S. BRYN AUSTIN, CHRISTINE M. PEAT, CYNTHIA M. BULIK, OPINION CONTRUBUTORS – 07/22/20 01:30 PM EDT

Op-ed placed in The Hill, daily news source widely read by federal policymakers

 Goal: Get key findings, call for policy action in go-to news source for lawmakers, federal agency staff Part 3: Bigger Picture

Translation to Policymakers

Contracted with Capitol Hill-based government relations
 & communications firms







Eating disorders cost US \$65 billion a year: Here's what agencies can do

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Translation to Policymakers



Eating disorders cost US \$65 billion a year: Here's what agencies can do

BY S. BRYN AUSTIN, CHRISTINE M. PEAT, CYNTHIA M. BULIK, OPINION CONTRUBUTORS — 07/22/20 01:30 PM EDT

Op-ed urged policy action to:

- 1) Begin systematic national surveillance of eating disorders
- 2) Increase research funding
- 3) Correct insurance coverage gaps within federal payer systems to ensure comprehensive eating disorders treatment coverage

Translation to Policymakers

 Government relations firm setting up meetings with federal agencies & major healthcare lobbying coalitions















Goals:

Translation to Policymakers

 Government relations firm setting up meetings with federal agencies & major healthcare lobbying coalitions















- Discuss key findings, options for policy action in meetings with policymakers themselves
- Leverage influence of major non-ED coalitions on Capitol Hill to amplify, reinforce our key asks

Our study has:

- Made critical steps toward more fully understanding social & economic burden of eating disorders in U.S.
- In addition, these new data will allow us to estimate:
 - Cost-effectiveness, improved quality of life, and most importantly, lives to be saved by scaling up effective prevention, early detection & treatment interventions

6

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- In addition, these new data will allow us to estimate:
 - Cost-effectiveness, improved quality of life, and most importantly, lives to be saved by scaling up effective prevention, early detection & treatment interventions
- From strategic science perspective, our top priority for undertaking impact report:
 - To engage decision makers in U.S. government, healthcare
 & other sectors to motivate them to take action

- U.S. policymakers have the evidentiary base to justify action
 - \$65 billion lost annually to the economy due to eating disorders
 - One life lost every 52 minutes
 - Escalating mental health crisis during COVID-19 pandemic further underscores urgency
- Responsibility for all of us in the U.S. now is to use methods of strategic science to motivate policymakers to act

69

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 - Escalating mental health crisis during COVID-19 pandemic further underscores urgency
- Responsibility for all of us in the U.S. now is to use methods of strategic science to motivate policymakers to act

The lives depending on us can't afford to wait

Q: Who will be next to generate similar impact report?

Canada?

 National Eating Disorders
 Information Centre investigating possibility of similar national report



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Q: Who will be next to generate similar impact report?

Canada?

 National Eating Disorders
 Information Centre investigating possibility of similar national report



• European Union?

 Academy for Eating Disorders' Unna Danner, Ursula Bailer & Gry Kjaersdam Telleus leading efforts to initiate EU report





Unna Danner



Ursula Bailer



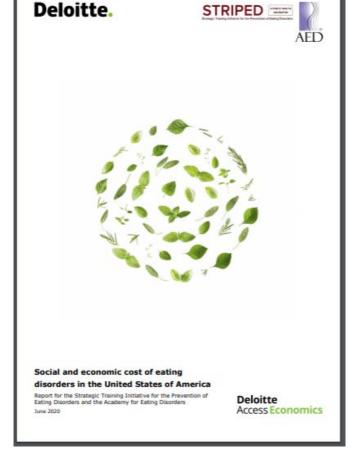
Gry Kjaersdam Telleus

Thank you!

To read report:

https://bit.ly/3jOviY8





Contact:

Bryn.Austin@childrens.harvard.edu

